The Impact of Child's Severity on Quality-of-Life among Parents of Children with Autism Spectrum Disorder: The Mediating Role of Optimism

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Objective: Investigate the impact of child severity and optimism on quality-of-life in parents of children with Autism Spectrum Disorder (ASD). Additionally, the role of optimism as mediator between child's severity and parental quality-of-life was also evaluated.

Material and Method: Three hundred three parents of children with ASD were recruited from the local autistic centers and schools in Bangkok, Thailand. A set of demographic information sheet, the Childhood Autism Rating Scale (CARS), the Life Oriented Test-Revised (LOT-R), and the WHOQOL-BREF test were submitted for collecting parental information.

Results: Using Pearson Correlation, a significant negative association was found between child's severity and parental quality-of-life while optimism was found to correlate positively with parental outcomes. The finding from path-analysis confirmed that impairment of language and repetitive behavior of an ASD child associated with optimism that, in turn, predicted level of parental quality-of-life in all domains.

Conclusion: The current findings assured a role of optimism as mediator between child's severity and parental quality-oflife. Implications for the development of intervention focused on enhancing parent's optimism were recommended.

Keywords: Autism spectrum disorder (ASD), Optimism, Quality-of-life, Mediating role

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Autism Spectrum Disorder (ASD) is the early childhood development disability which characterized by the criteria of DSM-IV-TR as a triad of impairments in social interaction, communication, restricted and repetitive pattern of behavior⁽¹⁾. ASD is a long-life condition; therefore parenting them brings about the great difficulties to parents. Previous studies revealed that parents of ASD children faced higher stress than the other two groups i.e. parents of children with other mental illness^(2,3) and parents of children with typical development^(4,5). While some studies revealed on several factors parents applied for the ASD-related situation, for example, coping pattern of parents, social support network, parental locus of control, parenting efficacy and satisfaction, and perception of family cohesiveness⁽⁶⁻⁸⁾.

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Tanasugarn C, Department of Health Education and Behavioral Sciences, Faculty of Public Health, Mahidol University, Bangkok 10400, Thailand. Phone: 0-2354-8548 E-mail: phctn@mahidol.ac.th However, it should be noted that little previous research had been carried on optimism as one of positive mechanism relation to adaptation of parents of children with ASD. Theoretically, optimism is an expectation that more good things will happen in the near future so that optimistic people will be able to pursue their valued goals and regulate themselves even in the face of difficulties⁽⁹⁾. Therefore, it is possible that focusing on optimism of parents when raising children with ASD will foster physiological, psychological, and social benefits as well as increase their overall quality-of-life as the ultimate goal.

Present study and hypotheses

The present study aims to investigate how the child's severity and optimism are associated with quality-of-life in parents of children with ASD. Four domains of quality-of-life are explored: (1) physical well-being, (2) psychological well-being, (3) social well-being, and (4) environmental well-being. The child's ASD severity as characterized by the DSM-IV-TR and optimism are evaluated as predictors to

parental quality-of-life. In addition, the authors investigate the potential mediating effect of optimism on parental quality-of-life associated with the child's severity. Based on literature, it should be hypothesized that the child's severity and optimism are the predictors to parental quality-of-life and the impact of child's severity on parental quality-of-life is mediated by optimism.

Material and Method *Participants*

Three hundred three parents of a child with ASD (71.3% mothers, 9.2% fathers, 14.5% grandparents, and 5.0% others) from the local autistic centers and schools in Bangkok, Thailand participated in this study. Numbers of sample were determined by fundamental formula of 10 cases per parameter (parameters included path coefficients, its variances, and the disturbance terms). In this study, there was 21 parameters therefore, a minimum of 210 cases was required. The purposive sampling method was used for recruiting participants, followed by the inclusion criteria of (1) they were main-caregivers to a child who were diagnosed as ASD by professional, and (2) they have been living with an ASD child in family.

Information regarding the parents was collected. The parents' age ranged from 19 to 70 years old with the mean of 43.17 (SD = 9.73) years. With respect to parents' educational level, 11.9% parents obtained Master Degree and above, 35.6% parents obtained a Bachelor Degree, 22.4% parents obtained a high school diploma, 25.4% parents completed primary school, and 4.7% parents did not respond to this item.

Information was also gathered about a child with ASD. The majority of them were males (76.6%) and ages ranged from two to 17 years old with the mean of 7.83 (SD = 3.46) years. The mean of age at diagnosis was 3.59 (SD = 2.33) years. The numbers of children living in the family ranged from 1 to 5 (55.2% one-child, 38.9% two-children, 4.3% three-children, 1.3% four-children, and 0.3% five-children, respectively). Most of children (91.4%) received some kinds of intervention/treatment with the average years of 4.71 (SD = 3.43).

Procedure

Participants were recruited with the support of local autistic centers and schools in Thailand. Three hundred ninety eight parents that had preliminary interests in being part of the research project were informed about research objective and its benefit. The cover letter explaining the study, the consent form and the ethical approval by the Institutional Review Board of Mahidol University were attached for consideration. Parents who were willing to participate were contacted and sent a set of questionnaires, including a demographic information sheet, the Childhood Autism Rating Scale (CARS), the Life Oriented Test-Revised (LOT-R), and the WHOQOL-BREF test. Three hundred eight parents completed and returned the questionnaires. Five subjects were removed from the study because of data missing. Therefore, 303 parents completed and remained in the analysis.

Measures

Demographic information

Participants were asked about his/her information regarding to the relationship to the child with ASD, his/her age, and level of education. They were also asked to report on the information of ASD child regarding to the age of a child, the age of a child at diagnosis, the gender of a child, the total number of children living in the family, and the years of receiving some kinds of intervention/treatment.

Child's ASD severity

The ASD symptoms were assessed by using the CARS test. It was a 15-item behavioral rating scale. Each item covered a particular characteristic or behavior (e.g. relationship to people, verbal communication, adaptation to change, visual response) and severity was rated on a 5-point scale ranging from 1 (normal for child's age) to 5 (extremely abnormal). Parents also rated their stressfulness related to each child symptoms on a 5-point scale ranging from 1 (not stress at all) to 5 (completely stress). The Cronbach's alpha for the test was 0.884, indicating high internal reliability.

Optimism

The LOT-R was employed for measuring optimism. It was a positive-based factor characterized by favorable personal future expectation. High score of LOT-R indicated parents who had greater optimism. The LOT-R consisted of six items (e.g. in uncertain times, I usually expect the best, I am always optimistic about the future). Parents were asked to rate on each item ranging from 1 (strongly disagree) to 5 (strongly agree). The Cronbach's alpha for the test was 0.860, indicating high internal reliability.

Parental quality-of-life

The WHOQOL-BRET test was employed for measuring quality-of-life in parents of children with ASD. It was the brief-version of WHOQOL-100 test developed by the World Health Organization in order to determine individual quality-of-life in general. The test was self-reporting and consisted of 26 items with 5-point scales. Four domains were divided in WHOQOL-BREF test, including (1) physical domain referred to degrees of physical well-being and less in physical health problems, (2) psychological domain referred to degrees of emotional and psychological well-being and less in emotional distress, (3) social domain referred to degrees of social function and satisfaction when individuals interact with others or when they participate in social situations, and (4) environmental domain referred to the extent to which individuals perceive environment as support and warmth. The Cronbach's alpha for the test was 0.930, indicating very high internal reliability.

Results

Demographic relationship

The correlation analysis between demographic and all variables of interest were tested in order to determine whether any demographic variables needed to be included in the analysis. Employing the Pearson correlation with the significant level of 0.05, it revealed that parent's age, child's age, and numbers of children in the family were not significantly related to any of the variables. Moreover, there were no significant differences between educational level of parents and any of variables in the current study. For these reasons, not all demographic variables existed in the model.

Demographic statistics and correlation

All variables in the current study were determined for their normality and linearity. The values of skewness and kurtosis were found to be normality distributed. The bivariate scatterplot presented as an oval-shape indicating linearity between variables. Therefore, it was more likely that the assumptions of multivariate analysis were all met. The descriptive statistics for each variable presented in Table 1. In general, parents of an ASD child reported extremely low quality-of-life in all domains when compared with norms⁽¹⁰⁾.

The relationship between variables used in the current study was presented in Table 2. Most of the intercorrelations were modest. Specifically, the significant negative association was found between child's severity and parental quality-of-life while optimism was found for positively correlating with parental quality-of-life. It indicated that parents who reported higher optimism were more likely to have good quality-of-life. In addition, the authors also found the positive association between child's severity and optimism variable.

Mediating analyses

The hypothesized model was drawn based on suggestion of previous study that optimism played a role of mediator between child's severity and parental outcomes. Therefore, in the first set of analyses, the path-analysis was employed to test whether optimism mediating the relationship between child's severity and parental quality-of-life as shown in Fig. 1. This result indicated poor level of model fit which consideration by multiple fit indices of Chi-square = 591.741, p-value <0.000, Chi-square/df ratio = 98.623, CFI = 0.341, GFI = 0.633, RMR = 2.884 and RMSEA = 0.569. Moreover, several non-significant associations between child's severity, optimism, and parental quality-of-life were found.

In the next set of mediating analyses, the nonsignificant pathways were deleted path-by-path from the model until only significant pathways left for analysis. The result, as shown in Fig. 2, indicated a good fit with the data (Chi-square = 16.735, p-value >0.05, Chi-square/df ratio = 1.521, CFI = 0.994, GFI = 0.986, RMR = 0.220 and RMSEA = 0.042). Several pathways between child's severity, optimism, and parental quality-of-life were presented. Repetitive behavior of an ASD child associated with lower level of physical and psychological well-being in parents. Optimism was positively associated with parental quality-of-life in all domains. In addition, the indirect

 Table 1. Descriptive statistics

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Variables in the study	Mean	SD	Range
Child's severity			
Social impairment	2.39	1.71	1-5
Communication impairment	2.60	1.49	1-5
Restricted and repetitive	1.93	1.65	1-5
behavior			
Optimism	2.55	1.55	1-5
Quality-of-life			
Physical well-being	25.92	3.58	13-35
Psychological well-being	22.12	3.51	6-30
Social well-being	10.65	1.69	3-15
Environmental well-being	27.72	4.48	12-40

Variables	1	2	ŝ	4	5	9	7	8
Social impair	1							
Communicate impair	0.558^{**} (<0.001)	1						
Repetitive behavior	$0.620^{**} (< 0.001)$	$0.443^{**} (< 0.001)$	1					
Optimism	0.133*(0.021)	$0.189^{**} (< 0.001)$	0.189** (<0.001) 0.162** (<0.001)	1				
Physical QoL	-0.005 (0.926)	-0.011 (0.853)	-0.131* (0.023)	0.107*(0.042)	1			
Psychological QoL	-0.017 (0.772)	0.003 (0.962)	-0.126* (0.028)	$0.130^{*}(0.024)$	0.130* (0.024) 0.710** (<0.001) 1	1		
Social QoL	0.003 (0.955)	0.093 (0.105)	-0.042 (0.466)	$0.136^{*}(0.018)$	0.574** (<0.001)	$0.136*(0.018)$ $0.574^{**}(<0.001)$ $0.589^{**}(<0.001)$ 1	1	
Environmental QoL	-0.043 (0.456)	-0.054 (0.353)	-0.102 (0.076)	(0.099)	0.572** (<0.001)	0.099 (0.086) 0.572** (<0.001) 0.707** (<0.001) 0.606** (<0.001)	$0.606^{**} (< 0.001)$	-
** p-value <0.01								
* p-value <0.05								

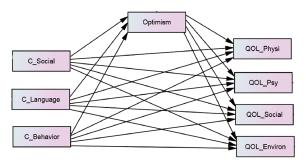


Fig. 1 Hypothesized model depicting optimism as a mediator of the relationship between child's severity and parental quality-of-life.

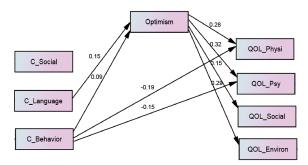


Fig. 2 Model result depicting optimism as a mediator of the relationship between child's severity and parental quality-of-life. Standardized path coefficients were presented. Only significant pathways were shown.

relationship between child's severity and parental outcomes were found. The impairment of language and repetitive behavior of an ASD child associated with optimism, this optimism in turn predicted level of parental quality-of-life in all domains. This finding suggested on optimism that it played a mediating role between child's severity and parental positive outcomes. The p-value of standardized direct effect of optimism on psychological well-being in parents was <0.01 whereas the p-value for all the pathways were <0.05. However, there was no direct and indirect effect found between social impairment of an ASD child, optimism, and any domains of parental quality-of-life.

Discussion

QoL = quality-of-life

One of the fundamental objectives of this study was to investigate the simple relationship between child's severity to parental outcomes as well as that between optimism and parental quality-of-life. Several previous studies indicated that the child's ASD severity and behavior predicted level of parental stress in all domains⁽¹¹⁻¹³⁾ and association with a decreasing in overall parental quality-of-life⁽¹⁴⁾. The current finding was consistent with the prior.

Regarding to the optimism variable, it is viewed as an expectation that more good things than bad will happen in the future. Optimism predicts individual's physical and mental health. The optimistic people also cope better with stress, actively avoid stressful life events, build up better social network, and have healthier life-style that prevents them from developing illness^(15,16). The findings in this study confirm that optimism is effective in increasing parental quality-of-life, especially in domain of physical, psychological, and social well-being. However, some finding of optimism did not consistent with a previous literature when it showed positive correlation between optimism and child's severity. The possible explanation might be due to selective method when participants were parents who were willing to be part of the project and they had brought children to get help already. Usually, those active parents often find the best way for their child and filled with positive expectation that the child will behave better, no matter how severe the symptoms the child were.

Although focusing on increasing optimism may be effective in fostering positive parental outcomes, the finding of the current study further suggests that optimism play a role of mediator between child's severity and parental quality-of-life. The causal direction of this relationship assures that optimism can help parents focus less on limitation of their ASD child, greater focus on positive aspects of the situation and this positive way of interpretation helps parents become more well-being. In addition, this finding correlates with previous studies in parents of children with ASD^(17,18).

However, this study has some limitations. First, the study was cross-sectional that did not include the impact of child's severity and optimism on parental quality-of-life overtime. Future study may employ longitudinal design to test and confirm existing causal pathways within the period of time. Second, the data collected through this study used self-reporting. This method may lead to recall bias when parents did not respond just by current answer, but by their memory. The recall bias may produce overestimate or underestimate response. Third, the purposive sampling method for recruiting participants in this study may lead to selective bias and limit the generalization, but it was a practical tool when participants were unique.

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Potential conflicts of interest

None.

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ผลกระทบของความรุนแรงของโรคในเด็กที่มีต่อคุณภาพชีวิตของผู้ปกครองที่มีบุตรเป็นโรคASD: บทบาทระหว่าง กลางของคุณลักษณะการมองโลกในแง่ดี

มานิกา วิเศษสาธร, ชะนวนทอง ธนสุกาญจน์, Edwin B Fisher

วัตถุประสงก์: เพื่อค้นหาผลกระทบจากความรุนแรงของโรคและการมองโลกในแง่ดีที่มีผลต่อระดับคุณภาพชีวิตของผู้ปกครองที่มี บุตรเป็นASD นอกจากนี้ยังได้ศึกษาถึงบทบาทระหว่างกลางของตัวแปรการมองโลกในแง่ดีที่มีอิทธิพลระหว่างความรุนแรงของโรค ในเด็ก และระดับคุณภาพชีวิตของผู้ปกครองด้วย

วัสดุและวิธีการ: กลุ่มตัวอย่าง ได้แก่ ผู้ปกครองที่มีบุตรเป็น ASD จำนวน 303 ราย จากศูนย์ออทิสติกและโรงเรียนที่มีห้องเรียน เด็กพิเศษในเขตกรุงเทพมหานคร ประเทศไทย เก็บข้อมูลผู้ปกครองด้วยชุดแบบสอบถาม ประกอบด้วย แบบข้อมูลส่วนบุคคล แบบทดสอบ Childhood Autism Rating Scale (CARS) แบบทดสอบ Life Oriented Test-Revised (LOT-R) และ แบบทดสอบ WHOQOL-BREF test

ผลการศึกษา: จากการวิเคราะห์ด้วยสถิติ Pearson Correlation พบว่าความรุนแรงของโรค ASD ในเด็กมีความสัมพันธ์ทางลบ กับระดับคุณภาพชีวิตของพ่อแม่ ในขณะที่ตัวแปรการมองโลกในแง่ดี มีความสัมพันธ์ทางบวกกับระดับคุณภาพชีวิต ส่วนผลการ ศึกษาด้วยการวิเคราะห์ path analysis ยืนยันว่าความบกพร่องด้านภาษาและการแสดงพฤติกรรมซ้ำ ๆ อย่างไม่มีความหมายของ เด็กที่เป็น ASD มีผลต่อระดับการมองโลกในแง่ดีของพ่อแม่ และระดับการมองโลกในแง่ดีนี้เองที่มีผลต่อเนื่องไปสู่ระดับคุณภาพ ชีวิตของพ่อแม่ในทุก ๆ ด้านต่อมา

สรุป: ผลจากการศึกษาครั้งนี้ยืนยันถึงบทบาทระหว่างกลางของการมองโลกในแง่ดี และจะเป็นประโยชน์ต่อการพัฒนาโปรแกรม เพื่อส่งเสริมคุณลักษณะการมองโลกในแง่ดีสำหรับพ่อแม่ที่มีบุตรเป็น ASD ต่อไป