

Relationships between Sense of Coherence, Coping Strategies and Quality of Life of Parents of Children with Autism in Malaysia: A Study of Chinese Parents

P.C. Siah¹, S.H. Tan²

1. Department of Psychology and Counseling, Universiti Tunku Abdul Rahman, Malaysia

2. Faculty of Education, Universiti Teknologi Malaysia, Malaysia

ABSTRACT

Purpose: This study aimed to examine the relationships between Sense of Coherence (SoC), Coping Strategies and Quality of Life (QoL) of parents of children with autism in Malaysia.

Method: Purposive sampling was used to recruit parents of children with autism from 3 Autism Centres run by NGOs. The parents were asked to complete a questionnaire.

Results: The results of the study show that SoC and cognitive reframing are important factors that are associated with QoL.

Conclusions: It is recommended that policy-makers and programmers at the Autism Centres conduct more training workshops for parents of children with Autism Spectrum Disorder (ASD), so that their overall QoL can be improved.

Limitations: Future studies could recruit more participants, especially parents at government centres.

Key words: Autism Centres, cognitive reframing, Brief COPE, WHOQoL.

INTRODUCTION

Autism Spectrum Disorder (ASD) is regarded as a spectrum of neurodevelopmental disorders (Jobe & White, 2007), since it includes clinical diagnosis of Autistic Disorder, Asperger's Syndrome and Pervasive Development Disorder – Not Otherwise Specified (Volker & Lopata, 2008; Berg & Plioplys, 2012). The major features of ASD include qualitative impairment in reciprocal social interactions, patterns of communication, and repetitive interests and activities which usually

* **Corresponding Author:** Associate Professor, Department of Psychology and Counseling, Universiti Tunku Abdul Rahman, Malaysia. Email:siahpc@gmail.com

present at the age of three (Volker & Lopata, 2008; Berg & Plioplys, 2012). Nonetheless, the etiology of ASD is still not clear and, as of today, there is still no cure for this disorder. Consequently, ASD is regarded as a lifelong condition (Elder & D'alessandro, 2009).

The prevalence rate of ASD has been increasing dramatically over the past two decades, which may be due to change of diagnostic criteria, policy and practice changes, and greater awareness of the disorder (Levy et al, 2009; McPartland et al, 2012). It is estimated that about 1 in 110 children have been diagnosed with ASD, and more males have been diagnosed than females, with the sex ratio being about 4 males:1 female (Giarelli et al, 2010). Nonetheless, ASD has been found across the socioeconomic continuum, and in all racial and ethnic groups (Bartley, 2006).

ASD is the fastest growing disorder in Malaysia. It is estimated that there are approximately 12,800 cases of autism, and 1 out of every 600 children in Malaysia is affected by ASD (Malaysian Psychiatric Association, 2010; Meadan et al, 2010; Sin Chew Daily, 2012). Since taking care of a child with ASD is a lifelong endeavour (Seltzer et al, 2004; Meirsschaut et al, 2010), parents of children with autism, especially the mothers, have been found to have higher prevalence of stress, psychological disturbances and depression (Azlina Wati Nikmat et al, 2008; Athari et al, 2013). These parents are also more likely to develop mental issues, depression, somatic complaints, feelings of social isolation and burnout (Hastings et al, 2007; Carter et al, 2009; Sipos et al, 2012).

Moreover, parents of children with ASD tend to experience marital strain and disrupted family life due to their children's challenging behaviour, as well as fewer opportunities to engage with their communities (Allik et al, 2006; Myers et al, 2009). These parents are nearly twice as likely to divorce as compared to parents who do not have a child with autism, due to poor family functioning and less marital happiness (Higgins et al, 2005; Hartley et al, 2010; Gau et al, 2012). Overall, the quality of life (QoL) of parents of children with autism is poor (Yamada et al, 2012).

QoL is an important measure for guiding health care (Collins et al, 1991), since it is a multidimensional concept that cannot be simply equated with health status, lifestyle, life satisfaction, mental state, or well-being (The WHOQOL Group, 1998). The World Health Organisation (1997) has defined QoL as the "individuals' perceptions in the context of their culture and value systems, and their personal

goals, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment".

Nonetheless, a better QoL was found among those parents who had a higher Sense of Coherence (SoC) (Olsson & Hwang, 2002). From the salutogenetic perspective, Antonovsky (1987) claimed that one can foresee the consequences of a specific stressor on an individual's health by understanding a person's view of herself / himself and the world. In other words, through the resistant resources or the factors that contribute to the development of SoC, one can understand the stressors and thus create a strong SoC (Volanen et al, 2004). SoC has been defined as - Global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that: (1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable (comprehensibility), (2) the resources are available to meet the demands posed by these stimuli (manageability), (3) these demands are challenges, worthy of investment and engagement and that life makes sense emotionally (meaningfulness) (Antonovsky, 1987). In other words, the three components of SoC are comprehensibility, manageability and meaningfulness (Mak et al, 2007; Pozo et al, 2011).

Comprehensibility is relevant to parents' information needs, such as their child's condition, the services available to them, and parents' accounts of their experiences (Oelofsen & Richardson, 2006). Meaningfulness involves a sense of worth in facing the challenges (Beresford, 1996; Olsson & Hwang, 2002). Manageability refers to the ability or the feeling that one will be able to obtain the necessary resources to handle situational demands (Pozo et al, 2011).

A person with a strong SoC would be able to foresee the consequences of a specific stressor on an individual's health (Antonovsky, 1987; Volanen et al, 2004). Parents who have a strong sense of meaningfulness view parenting their child with ASD as an enjoyable challenge, and have feelings of reward, pleasure of parenthood and a sense of moral responsibility (Beresford, 1996; Olsson & Hwang, 2002). Parents who have a strong sense of manageability would be able to access resources to assist them in handling behaviour problems of their children, and receive help and support from their spouse and from service centres (Bristol et al, 1993; Beresford, 1996).

Apart from the positive impact of a strong SoC, proper coping strategies are also found to assist parents of children with ASD to overcome their challenges (Paster et al, 2009). Lazarus and Folkman (1984) defined coping as “constantly changing cognitive and behavioural efforts in order to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person”. By using exploratory factor analysis, Benson (2010) extracted 4 factors from the 14 theoretically derived subscales of the Brief COPE, which were engagement, distraction, disengagement and cognitive reframing. Engagement is related to the individuals’ active involvement in addressing the stressful situations posed by their children with autism. Distraction includes strategies to distract oneself from the stressors. Disengagement is relevant to the attempts to deny or distance oneself from the situation. Lastly, cognitive reframing is relevant to the efforts to positively restructure or reframe beliefs about the stresses.

The coping strategies parents used to deal with their child’s autism included support from family and friends, joining support groups, connecting with other parents of children with autism, the use of service providers, advocacy and support groups and religion (DeMeyer, 1979; Gray, 2003; Hall & Graff, 2010). Studies also found significant associations between greater use of active-avoidance coping strategies with higher levels of depression, stress, and parenting stress (Paynter et al, 2013).

Studies have shown that those who apply positive coping strategies more frequently and resort to avoidance less frequently are people with a high level of SoC as they usually perceive stressors as positive challenges. In contrast, people who are more likely to use avoidance strategies to cope with the difficulties are those with a low level of SoC, as they usually perceive difficult situations as threats (Olsson & Hwang, 2002; Dakabrowska, 2008; Pisula & Kossakowska, 2010).

Objective

Review of literature by the author indicates that no study has explored the relationships between SoC, coping strategies and QoL of parents of children with ASD, especially in Malaysia.

This study therefore aimed to examine:

1. What is the relationship between SoC, coping strategies and QoL?
2. Whether SoC and coping strategies are associated with the QoL of parents of children with ASD in Malaysia?

The results of this study will provide information to policy-makers and NGO programmers, so that they can take these factors into consideration when planning strategies or programmes to improve the QoL of parents of children with ASD in Malaysia.

METHOD

This study was conducted at three Non-Governmental Organisations (NGOs) that provide services to children with ASD in Malaysia. Approvals were obtained from the person in charge of conducting the study at each organisation.

Procedure

Purposive sampling method was used to recruit participants who had a child or children with ASD. Special education teachers or instructors at the three NGOs distributed the questionnaires after they were briefed on the procedure for administering the survey. They were instructed to distribute the questionnaires to those who had given their written informed consent. Participants were allowed to answer the questionnaire either at home or at the organisation. A handmade soap purchased from a disability centre was given to those who completed and returned the questionnaires.

Participants

Of the 100 parents who were recruited, 96 returned the questionnaires. The final sample was 92 parents. Among the participants, 95.8% were Malaysian Chinese, 93% were married, 89.6% followed a religion, 75% were females, 58.3% were below 45 years of age, 46.9% had a full or part-time job, 41.9% had a monthly income above 4000 ringgits, and 39.6% had above secondary level education (see Table 1). Since most of the participants were Malaysian Chinese, only their data was included in data analyses to avoid over generalisation of the results.

Questionnaire

The questionnaire contained the following sections: demographic information, WHOQoL-BREF, SoC scale and Brief COPE.

Table 1: Demographic Background of Parents of Children with ASD (n = 96)

Age	Below 45	58.3%	Highest education	Secondary or below	49%
	45 or above	41.7%		Above secondary	39.6%
Gender	Male	25%	Marital status		
	Married	93%			
	Female	75%		Others	7%
Ethnic	Chinese	95.8%	Employment		
	Full or part time	46.9%			
	Malay or Indian	4.2%		Housewife or retired	53.1%
Religion	Buddhism	57.29%	Monthly household income		
	RM4000 or below	58.1%			
	Christianity	20.83%		Above RM4000	41.9%
	Others	12.5%			
	No	10.42%			

WHOQoL-BREF

The WHOQoL-BREF instrument contains 26 items categorised into four subscales: physical health, psychological health, social relationships, and environmental factor domains. There are four types of 5-point Likert interval scales in which the participants were asked to express 'how much', 'how completely', 'how often', 'how good' or 'how satisfied' they felt for each item in the last two weeks. The scoring guideline was followed; first, the three negatively phrased items were re-coded, and then the scores of each subscale were transformed on a scale from 0 -100 for comparison purposes (The WHOQOL Group, 1998).

SoC

SoC contains 13 items, of which 4 items are reverse scale. Participants were required to circle a number from 1- 7 to indicate the strength of their feelings toward each item; a higher score indicated a stronger SoC (Antonovsky, 1987, 1993). The internal reliability of the scale in this study is 0.772. Antonovsky (1993) suggested using one factor to explain the structure of the scale. The average score of these 13 items was thus used to indicate the levels of SoC among participants. A higher score indicates a better SoC.

Brief COPE

Brief COPE has 28 items (Carver, 1997). Eight items were used to measure "engagement", 8 items measured "distraction", 6 items measured "disengagement", and 6 items measured "cognitive reframing", as suggested by Benson (2010). Internal reliabilities for Brief COPE in this study were 0.73, 0.65, 0.76 and 0.67, in order. Respondents were required to rate each item on a 4-point Likert scale (1= I haven't been doing this at all, to 4= I have been doing this a lot) depending on how frequently they employ 28 different behaviours and cognitions when coping with a specific stressful situation. A higher score indicated more consistent use of the coping strategies.

RESULTS

Relationships between SoC, Coping strategies and QoL

The Pearson correlation was used to examine the relationships between SoC, coping strategies and QoL (see Table 2). The results showed that SoC was significantly correlated with all 4 domains of QoL, and was negatively correlated with the 2 coping strategies: distraction and disengagement. Disengagement was negatively correlated with psychological health but cognitive reframing was positively correlated with psychological health. Disengagement and distraction were negatively correlated with both the social relationship and environmental factors.

Table 2: Results of Pearson Correlations between SoC, Coping strategies and WHOQoL (n = 92)

Coping		SoC	Coping			
			Engage- ment	Distra- ction	Disengage- ment	Cognitive reframing
	Engagement	-0.104				
	Distraction	-.477***				
	Disengagement	-.427***				
	Cognitive reframing	-0.004				
QoL						
	Physical health	0.397***	-0.132	-0.150	-0.179	0.084
	Psychological health	0.550***	0.149	-0.178	-0.204*	0.311**
	Social relationships	0.501***	0.037	-0.229*	-0.244*	0.081
	Environmental factors	0.598***	0.094	-0.190*	-0.317**	0.187
	Total QoL	0.590***				

Note: * $p < 0.05$ ** $p < 0.01$ *** $p < 0.001$

Multiple Regressions of SoC, Coping strategies and Demographic factors on QoL

Since total QoL is positively correlated with the all 4 domains of QoL, hierarchical multiple regression programmes were then used to examine the relationships between SoC, coping strategies and demographic factors on total QoL of parents of children with ASD. The results are shown in Table 3. In the first model, only SoC was entered by using enter method. The results showed that the first model is significant and explained 34.6% of total variance, $F(1, 87) = 45.95$, $p < 0.001$. SoC was significantly associated with total QoL, $\beta = 0.588$, $t = 6.78$, $p < 0.001$. In the second model, the 4 coping strategies were entered by using stepwise method for the selection of significant coping strategies. The results showed that the second model is significant and explained 38.4% of total variance, $F(2, 86) = 26.75$, $p < 0.001$. SoC was still significantly associated with total QoL, $\beta = 0.589$, $t = 6.96$, $p < 0.001$, but only cognitive reframing was included as a significant predictor, $\beta = 0.195$, $t = 2.31$, $p = 0.024$. In the third model, using the stepwise method 5 demographic factors were entered, which are age, gender, employment status (employed vs. unemployed or housewife), highest education (secondary or below

vs. above secondary) and monthly income (RM4000 or below vs. above RM4000). However, none of these background factors were accepted in the model.

Table 3: Multiple Regressions of SoC, Coping Strategies and Demographic Factors on total QoL

		Models	
		1	2
Predictors		β	B
SoC		0.588***	0.589***
Coping styles			
	Cognitive reframing		0.195*
F		45.95***	26.75***
df		1, 87	2, 86
R2		0.346	0.384
R2 change			0.038*

Notes: The coefficients shown are standardised betas.

* $p < 0.05$ ** $p < 0.01$ *** $p < 0.001$

DISCUSSION

Studies have shown that most parents of children with ASD face more stress and have a poorer QoL than other parents. However, some parents who have a better SoC or have employed appropriate coping strategies are found to be able to maintain or even improve their QoL. This study, therefore, aimed to examine the relationships between SoC, coping strategies and QoL among parents of children with ASD. To the author's knowledge, no study has explored the relationships of these 3 variables among parents of children with ASD, especially in Malaysia.

Firstly, the SoC is associated not only with psychological health, but also with the QoL of physical health, social relationships and environment. In other words, it is suggested that SoC is an important factor that is associated with different dimensions of QoL among these parents of children with ASD. These results support the conclusion that SoC is an important health promoting resource that is able to develop a positive subjective state of health (Eriksson & Lindström, 2005). Importantly, this conclusion can also be generalised to the parents of children with ASD in Malaysia.

Besides SoC, different coping strategies were also relevant to different domains of QoL, except for the engagement coping strategy. Nonetheless, while putting all these coping strategies in to the regression model for predicting total QoL, only cognitive reframing emerged as a significant predictor. The results suggested that parents of children with ASD who have a good overall QoL are those who have a strong SoC and use more cognitive reframing strategies. The results of regression in model 3 suggested that these relationships were not relevant to their demographic backgrounds.

CONCLUSION

Based on the findings, it is suggested that policy-makers and programmers at NGOs conduct more workshops to train parents of children with ASD to improve their SoC and to encourage their use of cognitive reframing coping strategies. This will help improve the overall QoL of those who have poor QoL. Future studies could consider recruiting a larger number of participants, especially parents at government centres, since this study sample consisted mainly of those who could afford the service charges of the non-government related autism centres. Future studies could also consider recruiting more participants from other ethnic backgrounds, such as Malays and Indians, so that more comparisons can be made.

Since purposive sampling was used, the findings of this study may be generalised with caution to parents who send their children to government centres where the charges are low, and also to all Chinese parents of children with autism in Malaysia.

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