

A Survey on Quality of Life and Situational Motivation among Parents of Children with Autism Spectrum Disorder in Malaysia

Poh-Chua Sian¹⁺ and Siew-Huei Tan²

¹University Tunku Abdul Rahman

²University Technology Malaysia

Abstract. This study aimed to examine the relationship between quality of life (QoL) and situational motivation (SIMS) adopted by parents of children with autism spectrum disorder (ASD). Participants were 47 parents who had at least one son or daughter with ASD, and were recruited from 3 NGOs in Malaysia. Approval from person in charge of the 3 NGOs and informed consent from participants were obtained before conducting the study. Purposive sampling was used to select participants, and questionnaire survey method was used to collect data. In the questionnaire participants needed to fill in their demographic information and 2 scales - the WHOQOL-BREF and the SIMS. The results found that more parents with high intrinsic motivation to participate in the program have better social relationships than those with low intrinsic motivation, and more parents with high identified regulation to participate in the program have better physical health than those with low identified regulation. No such association was found in those parents who participated in the programs due to the external regulation and motivation. This finding can provide a better understanding of how motivation relates to QoL among parents of children with ASD. Programmers at NGOs may consider applying the findings into their programs and policies to improve the QoL of parents of children with ASD.

Keywords: ASD, Parents, Coping Strategies, QoL.

1. Introduction

1.1. Situational Motivation

Psychologists are interested in the causes that make people perform certain types of behaviors. Motivation is an important construct that links with behaviors. Basically, motivation is defined as the energy, direction, persistence, and intentionality that direct biological, cognitive, and psychological functioning [1]. Among different motivational theories, self-determination theory (SDT) may be one of the more complete theories. The SDT believes the foundation of motivation includes the needs for competence, relatedness, and autonomy [2–4]. The need for competence is a basic desire of humans to be competitive while coping with their environment. The need for relatedness is a person's desire to interact with and care for others, as well as experience feelings of belongingness. The need for autonomy is a person's universal urge to be causal agents of their actions [2–4].

SDT aims to explain human behavior through the understanding of three types of human motivation: intrinsic motivation, extrinsic motivation, and amotivation [5]. Individuals with intrinsic motivation will engage in an activity that they feel is enjoyable [5], [6]. Individuals with extrinsic motivation will take part in an activity that allows them to gain reward or approval, or avoid guilt feelings [7]. In contrast, individuals who are amotivated will not participate in an activity, since they do not see any relationship between their actions and the outcome of their behaviors and thus they feel that there is no reason to do so [8].

Situational motivation (SIMS) is a motivation that individuals experience while they engage in an activity [8]. The SIMS scale is a scale that originates from SDT that has been applied in different settings, such as determining the effects of choice and goal orientations in physical activity [9–11]. SIMS measures four types of motivation: intrinsic motivation, identified regulation, external regulation, and amotivation [10].

⁺ Corresponding author. Tel.: + 146605789.
E-mail address: siahpcgm@gmail.com.

The identified regulation is a motivation relevant to one's personal identity and values, whereas external regulation occurs when a person engages in behaviours to gain rewards or to avoid punishment [1], [5], [12]. The SIMS has been found to have a good reliability and validity in both field and laboratory settings [10], [11].

1.2. Quality of Life

Quality of life (QoL) is a term which was first used after the Second World War, and it has emerged as an important outcome in guiding health care [13]. Nonetheless, many articles define the concept differently [1], such as well-being, objective conditions of living of an individual, or a person's experience of life. The different definitions can be attributed to many researchers from different disciplines who have contributed to the development of the concept and measurement of QoL [2].

Researchers believe that QoL can be measured through objective indicators, since it can be conceptualized as a construct that is multidimensional and influenced by personal and environmental actors and their interactions [14]. Importantly, most of them claim that QoL has the same basic composition for all people, and is enhanced by self-determination, resources, purpose in life, and a sense of belonging [15], even though there is still an ongoing debate regarding what the domains of experience of QoL are [16].

In this study, we adopted the definition from World Health Organization (WHO). According to WHO, QoL is defined as the individual's perceptions in the context of their culture and value systems, and their personal goals, standards, and concerns. It is a broad -ranging concept that is affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship with salient features of their environment [17].

1.3. Autism Spectrum Disorder

Autism spectrum disorder (ASD) has been dramatically increasing worldwide, with an estimated prevalence of 1 in 110 children over the past two decades [18]. ASD is the fastest growth disorder in Malaysia; there are approximately 12,800 cases of autism in Malaysia [19], and it is expected that one out of 600 children in Malaysia has been affected by ASD [20]. The increasing prevalence rate of ASD might be relevant to the changing of diagnostic criteria, policy, and practice changes [21]. The government and the public has realized the increasing number of children diagnosed with ASD, and especially the impact of autism on the family [22].

ASD is a spectrum of neuro-developmental disorders which include clinical diagnoses of Autistic Disorder, Asperger's syndrome, and Pervasive Development Disorder – Not Otherwise Specified (PDD-NOS) [23]. The major features of ASD are qualitative impairment in reciprocal social interactions, patterns of communication, and repetitive interests and activities [24], and these features usually present at the age of 3 [25]. In general, the sex ratio for ASD is higher for males than females, and is approximately 4 to 1 [26]. ASD has been found in all racial and ethnic groups, as well as across the socioeconomic continuum [27].

The physical health of the parents of children with ASD is influenced by taking care of their children with ASD [28]. For example, the wakefulness of their children might cause the parents not to have enough sleep, and the requirements to assist their children with ASD in daily chores such as transfer, toileting, and bathing can cause low back pain and wrist pain among the parents [29]. Therefore, the need to provide intensive care and attention to children with ASD has caused many parents of children with ASD to become physically exhausted, and they may also develop chronic pain [28].

In addition, many parents of children with ASD also showed lower QoL in the psychological domain. The slow improvement or progress of children with ASD may cause parents become depressed and frustrated, and the future of their children also worries the parents, as they will not able to manage their children as they get older [28]. The various problems that can come with having a child with ASD, including marital strain, the burden of constant care and supervision, school struggles, challenging behaviors exhibit by their ASD child, not being able to go anywhere, and disrupted family life, have caused many parents of children with

ASD to experience stress and feel weary, lacking in energy, worried, depressed, angry, or frustrated [29], [30].

1.4. Aims of the Study

Many programs have been developed to assist the parents of children with ASD to cope with their stress and to improve their QoL. Nonetheless, these programs are only effective when the parents of children with ASD have the motivation to participate in the programs. In other words, QoL of parents with ASD can only be improved when the parents have the motivation to participate these programs. However, even if they participate, different motivation for this participation may cause different effects. We believe that different motivations for participating in these programs influence the QoL of the parents. This study aimed to find the association between different types of motivation and QoL of parents of children with ASD. Through the findings, program developers can consider the different motivations of parents to participate in the programs so that their QoL can be improved.

2. Method

2.1. Participants

A sample of 47 parents of children with ASD was recruited through three non-governmental organizations (NGOs) in Malaysia for this study. About 74% were age 36 or above, and 77% were female. About 37% have an educational background above secondary school.

2.2. Apparatus

Demographic information. In this section, parents need to provide their demographic information, such as their age, gender, race, and marital status.

SIMS. The SIMS is a 16-item self-report inventory. Participants need to circle a number from 1 to 7 (1=corresponds not all to 7=corresponds exactly) to say how closely the description provided by the items matches their reasons for participating the program. A higher number indicates a better description of their reasons. The SIMS measures four types of motivation: intrinsic motivation, identified regulation, external regulation, and amotivation. Each type of motivation involves four items.

WHOQOL-BREF. The World Health Organization Quality of Life Schedule Brief version (WHOQOL-BREF) is a shorter version of the WHOQOL-100. The WHOQOL-BREF instrument contains a total of 26 items, which can be categorized into 4 subscales: physical health, psychological health, social relationships, and environmental factor domains.

2.3. Procedure

This study was conducted at three nongovernmental organizations (NGOs) located in Malaysia. Approval for conducting the study at the organizations was obtained from the person in charge. Participants were recruited through purposive sampling so that only those parents having a child with ASD were invited. Written informed consents were obtained from the participants before distributing the questionnaires to them to fill in. The questionnaires were distributed by special education teachers or instructors at the three NGOs. Briefings and instructions were given to those teachers or instructors. Researchers also answered questions that may arise from participants during the administration of the study. Participants could answer the questionnaire either in their homes or in the organizations. A token was given to those participants who completed and returned the questionnaires.

3. Results

3.1. Situational Motivation and QoL

Firstly, we divided participants into high and low QoL based on their median scores in the four domains of QoL. Secondly, we divided participants into high and low situational motivation based on their median

scores at the four types of motivation. After that, we ran a chi-square test for independence to examine the association between situational motivation and QoL. It can be seen in Table 1 that more participants with higher intrinsic motivation have a better social relationship than those with lower intrinsic motivation (36% vs. 9.1%), $X^2(1, n = 47) = 4.73, p = 0.03$. In addition, more participants with higher identified regulation have a better physical health than those with lower identified regulation (54.2% vs. 21.7%), $X^2(1, n = 47) = 5.23, p = 0.022$. No other significant result emerged.

Table1: The Association between Situational Motivation and QoL

	<u>intrinsic motivation</u>		<u>identify regulation</u>		<u>external regulation</u>		<u>amotivation</u>	
	High	Low	High	Low	High	Low	High	Low
Physical health	40	36.4	54.2	21.7*	48	27.3	37.5	39.1
Psychological health	52	59.1	62.5	47.8	68	40.9	50	60.9
Social relationship	36	9.1*	33.3	13	28	18.2	25	21.7
environment	64	54.5	66.7	52.2	64	54.5	54.2	65.2

Note: Numbers indicate percentages of participants with high QoL (* $p < .05$)

4. Discussion

This study aimed to examine any significant association between situational motivation and QoL. We expected that those parents who participated in programs based on their intrinsic motivation and identified regulation would have a better QoL. The results supported these expectations. However, the results can only be found in certain domains of QoL. Most parents of children with ASD who participated in the programs based on a high intrinsic motivation have better social relationships, and those who participated in the programs based on a high identified regulation have better physical health. No such different QoL was found in those parents who participated in the programs due to the external regulation and amotivation. Therefore, it is suggested that program developers elicit an internal motivation from parents to participate in the programs, as the use of external regulation would not result in different effects even if the parents participate in the programs. There are some potential limitations to highlight concerning the results of this study. A primary limitation of this investigation is that this was the first time the SIMS was used to measure motivation in parents of children with ASD. Although the scale had already been used in other contexts, no previous results existed against which to compare a population of parents of children with ASD. While the instrument holds merit for other populations of parents of children with ASD, until it receives further use with a population of parents of children with ASD, future researchers should begin with the application of the SIMS to other samples of parents of children with ASD. The intent of this recommendation is to establish the SIMS as a reliable measuring tool of motivation in parents of children with ASD. From this reliable starting point, accurate inferences can then be made about populations of parents of children with ASD. Another limitation is that the sample size in this study was too small, which might cause underrepresentation of the results and these findings may not be generalizable to other samples of parents of children with ASD. Researchers who wish to further examine this topic are advised to expand the sample size.

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