

RESEARCH ARTICLE

Leisure participation among parents of children with special needs

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Abstract:

Restrictions to engage in leisure participation were commonly cited in previous studies especially those with children with special needs (SNC). This study aimed to determine the level of leisure participation among parents with SNC and to examine the differences between the mothers' and fathers' leisure participation and whether there is an association between the level of leisure participation and the type of child's disability. Seventy-five participants completed a questionnaire with demographic information and the Modified Interest Checklist used to evaluate leisure participation in the past, present and future. Participants showed moderate level of leisure participation and the highest participation among the activities listed were in the activities of daily living (ADL) group. The differences among the activities participated between mothers and fathers were significant, with mothers showing highest participation in ADL. However, the level of leisure participation among the parents did not show any association with the types of child's disability that they reared. Professional healthcare should not only consider the intervention progress for the child, but also the parents' leisure participation in an effort to produce the best outcome for the child itself.

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1. INTRODUCTION

Leisure participation was defined as relaxing and enjoying activities carried out during the free time to relieve stress from daily responsibilities. It was mentioned that engaging in meaningful activities gives individuals opportunities to express creativity, experience a sense of accomplishment, and find joy (Eakman et al., 2010). From the occupational therapy (OT) perspective, leisure is defined as a "nonobligatory activity that is intrinsically motivated and engaged in during discretionary time, that is, time not committed to obligatory occupations such as work, self-care or sleep" (Pedretti et al., 2013).

Although many studies had explored the abundant benefits of engaging in leisure participation, it was still known as a limitation among the parents of SNC as they are restricted to engage in leisure time. One of the reasons that restricted the parents to engage in leisure time was because they are too emotionally and physically invested in the children's lives more than themselves as the children often demand a high level of psychological and emotional investment from their parents (Kim et al, 2018). They also reported that the moment they wake up till the children fall asleep, they sacrifice themselves to manage their children most of the time. They also had to cancel plans at the last minute if other emergencies regarding their children came up (Kim et al., 2018; Wozencroft et al., 2017).

In Malaysia, it was reported that parents with SNC experienced many challenges that contributed to the exclusion, and among them was the widespread perceived negative attitude from the society. Though it was not the major challenge faced by the parents, the social support for these parents was important to maintain function in leisure engagement. Due to the lack of knowledge among Malaysians regarding children with disabilities, they misjudged these children and some also feared this population (Ibrahim et al., 2019). Low et al. (2021) studied the level of knowledge of the public about autism spectrum disorder (ASD) and found that people mostly understand the category of SNC but were unable to comprehend the specific symptoms and manifestations of these children. Parents also reported difficulty to explain the nature of the condition to what the children needed to function in society (Suriati et. al., 2011).

Both mothers and fathers of SNC were reported to have restrictions in their leisure time. Mothers were reported to have higher restrictions on leisure participation compared to fathers. This is due to the responsibilities on child care that hold by the mothers as the primary caregiver compared to fathers (Musick et al, 2016). There was also a comparison of leisure participation that was evident between the types of disabilities of the SNC. Mother of children with hearing impairment and social limitation were less participate in leisure since they concern for the child's development,

communication, and community’s acceptance in the future social environment (Aras et al., 2014).

There are negative impacts to parents of SNC which they perceived of high burden related to the caring burden, less quality time with family and themselves, educational and future concerns, and financial difficulties (Shirley et al., 2017).

Parents always tried their best to provide for their children in return for their roles and responsibilities as parents. However, parents with SNC had to challenge themselves in multitasking to be prioritizing caregiving for their children rather than taking part in their leisure, the so-called 'me time' (Kim et al., 2018). Not only that, but they also rarely had time to engage in personal leisure, or if they had some free time, they would spend it monitoring or obtaining additional information or resources for their children (Kim et al., 2018). They had to spend additional hours fulfilling their children’s needs and as a result, disrupt not only the parents’ engagement in leisure but also their work and career (Kim et al., 2018). If this problem remains unresolved, it may affect the family institution and harmonization between the family members leading to a bigger issue in the future (Kim et al., 2018).

Mitchell et al. (2021) also discovered that leisure participation could also be influenced by the individual’s demographic background, especially if they had low levels of psychological problems. This was explained by the higher intimacy level between the family members, hence contributing to the higher participation in family leisure.

Most previous studies had studied regarding the reasons of leisure engagement limitations rather than the level of leisure participation among the parents. Thus, this study was conducted with its own purpose which are: 1) to determine the level of leisure participation among the parents of SNC, 2) to determine the differences between mothers’ and fathers’ leisure participation and 3) to determine whether there is an association between level of leisure participation among the parents and the type of the children’ disability.

2. MATERIALS AND METHODS

Methods

Participants

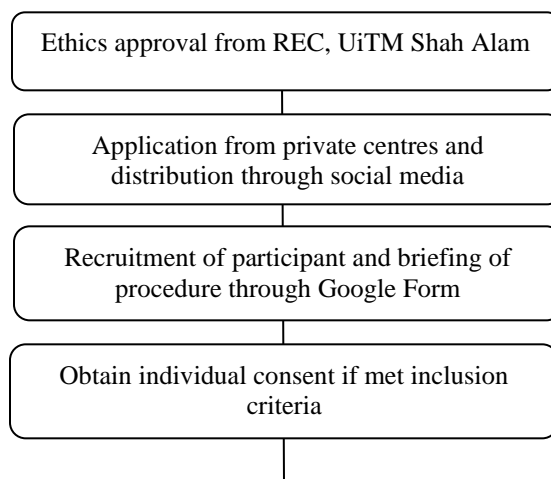
Seventy-five participants among parents with SNC participated in this study from a targeted of 178 parents. They were enrolled through a purposive sampling strategy. The inclusion criteria of participants include parents of SNC with their SNC aged between 0 – 12 years old; have been diagnosed with a disability; parents of SNC that are able to understand simple English in order to answer the questionnaire and parents of SNC who raising their children since birth to date.

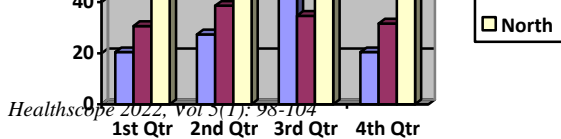
Instrumentation

The questionnaire in this study was modified by Kielhofner et al., (1983) which the Modified Interest Checklist was an adaptation of the Interest Checklist developed by Matsutsuyu in 1969. It is one of the Model of Human Occupation Screening (MOHO) assessment tools which integrated the aspects of human behavior based on the OT practice namely volition, habituation, and performance capacity, and attempted to understand the occupation together with the social and physical environment. The activities in this checklist were divided into five categories; Manual Skills, Physical Sports, Social Recreation, ADL, and Cultural or Educational which consisted of interest and engagement in 68 activities in the past, currently, and in the future. The questionnaire was provided in English language, and the participants were required to answer two parts; a) demographic data and b) Modified Interest Checklist. The demographic part consisted of personal questions regarding the participants such as the client’s age, number of children, level of education, working hours and others. For the second part, Modified Interest Checklist was used to obtain information regarding the participants’ leisure engagement in the past, present and future (Kielhofner et al., 1983). The duration of answering the question is approximately between ten to fifteen minutes.

Procedure

This research was approved by the Research Ethics Committee (REC), Universiti Teknologi MARA (UiTM), Shah Alam (REC/12/2021 (UG/MR/1170) and all participants were required to sign the informed consent before participating in the study. This cross-sectional study distributed questionnaire in the form of Google Form through social media (eg: Facebook, Whatsapp). Potential participants were obtained from private centres that cater for SNC and screened through list of inclusion and exclusion criteria to be fulfilled at the beginning of the questionnaire before proceeding to the next part, answering the survey. Then, they were briefed regarding the study on the first page of the Google Form and individual consents were obtained when the potential participants clicked on then ‘Next’ button. This study took about 6 weeks of data collection process for enrolling the participants. Figure 1 indicated the flowchart of data collection procedure.





Data collection and data analysis using SPSS

Figure 1. Flowchart of data collection procedure

Data analysis

The data was recorded in the excel when the participants clicked 'Submit'. The data was downloaded in excel format and then analysed using the Statistical Package for Social Sciences (SPSS) version 26.0.

To analyse the first objective, descriptive test was used to investigate the level of leisure participation among the parents. The level of leisure participation was analysed using the participants' answers of the current participation among all the activities listed.

Next, to analyse the differences between the mothers and father level of leisure participation, independent T-test was used, and the data used was the current participation in the activities among mothers and fathers.

The final objective was analysed using the Chi-Square test, by comparing the level of current participation among the parents between the types of child's disabilities.

3. RESULTS AND DISCUSSION

Based on Table 1 demographic of the respondents, n=28 were male (37.3%) participants, with majority aged between thirty to thirty-nine years old. More than half of the participants had tertiary education. Most of the children reared by the participants were categorized in the mentally disabled group, followed by multiple disabilities.

Table 1. Demographic data for parents of SNC (n=75)

Variables		(n)	(%)
Age group	<20 years old	3	4.0
	20-29 years old	23	30.7
	30-39 years old	24	32.0
	40-49 years old	19	25.3
	50-59 years old	5	6.7
	60-69 years old	1	1.3
	>70 years old	0	0
Category of parenthood	Mother	47	62.7
	Father	28	37.3
Level of education	Primary education	3	4.0
	Secondary education	13	17.3
	Tertiary education	59	78.7

Type of child's disability	Hearing impairment	7	9.3
	Visual impairment	2	2.7
	Speech impairment	6	8.0
	Physical disabilities	10	13.3
	Learning disabilities	7	9.3
	Mental disabilities	27	36.0
	Multiple disabilities	16	21.3

The activities listed were up to the parents' interpretations and parents were given their own freedom to answer the questions.

Before the data was analysed in the SPSS, all the activities as listed and categorized in the Modified Interest Checklist into five groups as referred from Casal (1999) and Cyganik (1996):

- 1) Activities of Daily Living (ADL) (basic domestic activities)
- 2) Manual skills incorporate use of the hand skills to produce end products)
- 3) Sports (incorporation of physical requirements such as strength, agility, stamina)
- 4) Educational/cultural (training, development and refinement of the mind)
- 5) Social recreation (participation with other individuals in interesting exercise or occupation)

Through these categories, the objectives of the study can be easily concluded. The result and discussion of the study will be referred to the categories for any conclusions.

3.1 Level of leisure participation among parents with SNC

Since there are more than fifty activities listed in the Modified Interest Checklists, only three highest activities participation in each group were listed in the manuscript.

The result showed highest participation in the ADL activities, with the highest in childcare (93.3%), followed by laundry (80.0%) and driving (77.3), while the other groups had the highest participation of not more than 70%. This may be explained by the fact that the activities listed in the ADL group are integrated in their daily lives (Ermisch, 2014), leading to higher participation. As reported in the findings in the first objective, childcare seems to be the activity with the highest level of participation among the parents. Other than that, since almost 2/3 of the participants were mothers, the high level of participation in the activity may also affect the result of the first objective reflecting themselves as the primary caregiver. The example was given in a previous study by Hewson (2010) explaining that women who reared a child tend to integrate the child's intervention session during their ADL activities (Hewson, 2010).

For manual skills, the numbers of participation were the lowest compared to the other groups, which is the handicraft

(32%), followed by model building (8%) and camping (6.7%). The participation among the parents in this group might be influenced by the nature of the activities that takes a long time to complete, contradicting with the parent’s availability to perform the activity even with their children.

In the sports group, exercise had the highest level of engagement among the parents with 65.3%, followed by walking (64%) and cycling (30.7%). This is not surprising, as Malaysians were physically active by exercising and walking (Hulteen et al., 2017; Razak et al., 2013; Teh et al., 2014). The activities were not only simple and easy, but parents can also bring their children with them for sensory exploration outside, which in turn benefits the children, explaining the high level of participation among the parents.

In the educational/recreational group, 48 parents claimed to have participated in reading (64%), followed by 47 parents in foreign languages (62.7%) and 42 participants in church activities (57.3%). The activities in the educational/recreational group might be an attempt from the parents’ perspectives to develop good habits among their children. From the results, the highest participation was reading, foreign languages and church activities, which activities that commonly begins during childhood.

In the social recreation group, watching television recorded the highest number of participations among the parents. In Malaysia, watching television is a common leisure activity, and while it is a passive activity, the parents can take the time to watch their favourite shows while their children were sleeping or resting, hence they are more inclined to watch television during their free time. even if their children were not sleeping or resting, they can attract their children to watch the show with them and share their own quality time through watching television. This finding was supported by Buswell et al. (2012) that suggested child-parent leisure participation is mostly home-based activities, as the focus of the parent is to spend some quality time and be there physically with their children. (Harrington, 2014; Buswell et al., 2012).

Table 2. Three highest level of participation among parents of SNC in every category

	Activities	(n)	%
ADL	Childcare	70	93.3
	Laundry	61	80
	Driving	58	77.3
Manual skills	Handicrafts	23	32
	Model building	6	8
	Camping	5	6.7

Sports	Exercise	49	65.3
	Walking	47	64
	Cycling	22	30.7
Educational/recreation	Reading	48	64
	Foreign languages	47	62.7
	Church activities	42	57.3
Social recreation	Television	51	68
	Visiting	50	66.7
	Holiday	48	64

3.2 Level of leisure participation between mothers and fathers of SNC

In this subchapter, the activities that showed differences in the level of participation between mothers and fathers will be discussed. Among all groups, a few activities in the ADL, manual skills and social recreation group showed differences. The other groups, sports and educational/ recreation group showed no differences in any of the activities.

In the ADL group, all the activities that reported significant differences showed higher participation towards mothers compared to fathers, except for home repairs. Females are more frequently to be the home maintainer are more likely to be associated with home-based activities even while rearing a child. This is because they feel a higher sense of responsibility as a family caretaker (as cited in Cheah & Poh,

Table 3. Activities that showed significant differences between mothers and fathers participation level

	Activities	Mothers Mean (SD)	Fathers Mean (SD)
ADL	Sewing	1.89 (0.315)	1.49 (0.505)
	Cleaning house	1.50 (0.509)	1.11 (0.312)
	Laundry	1.39 (0.497)	1.09 (0.282)
	Home decorating	1.79 (0.418)	1.36 (0.486)
	Clothes	1.82 (0.390)	1.47 (0.504)
	Cooking/baking	1.61	1.13

		(0.497)	(0.337)
	Shopping	1.64 (0.488)	1.15 (0.360)
	Home repairs	1.61 (0.497)	1.89 (0.312)
Manual skills	Woodworking	1.89 (0.315)	1.98 (0.146)
Social recreation	Attending plays	1.91 (0.282)	2.00 (0.000)
	Parties	1.85 (0.360)	2.00 (0.000)
	Chess	1.91 (0.282)	1.68 (0.476)
	Dancing	1.94 (0.247)	2.00 (0.000)
	Listening to music	1.75 (0.441)	1.51 (0.505)

2014; as cited in Craig & Churchill, 2020). Since women are more easily stressed by their own environment, they take care of their surroundings at a higher level than men. This explains the fact that they are more likely to engage in house activities. The result can also be explained by the higher level of female participation, thus the level of participation among male could not be determined. However, for home repair, the father showed higher participation as it is considered to be heavy work and out-of-home maintenance, and mothers had to work and rear their children, hence the responsibilities were given to fathers.

The only activity in the manual skills group that showed significant differences between mothers and fathers was woodworking. Mothers showed lower mean and SD (M=1.89; SD=0.315) compared to fathers with higher mean and SD (M=1.98; SD=0.146). This result may be due to the reason that woodworking is known to be heavy work and needs male's energy level compared to female. Another reason to justify the higher participation among fathers may be due to insufficient time for women's involvement as they are more attached to work and childcare, making them have difficulties engaging in the activity when they have any free time (Yin-Fah et al., 2013).

In the social recreational group, fathers are more likely to engage in plays, parties, dancing, and listening to music. This could be explained because the male counterparts have more freedom to access cultural activities, and they are not fussy as they pampered their children more than their wives. Gracia (2015) said that fathers are not influenced by any other factors such as the mothers' social status while engaging in any cultural activities (Gracia, 2015).

3.3 Association between leisure participation and the type

of child's disabilities

As for this objective, there was no association recorded between the leisure participation of parents (in each aspect of ADL, manual skills, sports, educational/recreation and social recreation) towards the type of child's disability. There were also lack of previous study explaining the relationship between the two variables, hence no arguments nor conclusions can be made. However, it was noted that most of the studies supported the conclusion that parents with SNC had a low level of leisure participation despite any type of disabilities (Cappe et al., 2018; Chu et al., 2020; Hatzmann et al., 2013; Kim et al., 2018; Marsack-Topolewski & Church, 2019). Other than that, the objective of the study only discovered the type of leisure participation in relation to the child's disability instead of the level of leisure of participation with the child's disability, thus showing no significant results.

4. CONCLUSION

This study indicated that parent's engagement in leisure activities were seen as half of them participated in most of the those activities Parents of SNC are heavily affected as many of them showed difficulty in juggling between their own responsibilities, such as taking care of their children

Based on this study, we can conclude that although the parents still engage in leisure activities, the results showed moderate to low level of engagement in the activities, except for ADL activities as they had to perform it daily. Mothers, as the primary family caretaker showed higher participation in ADL compared to fathers, and fathers are more likely to engage in social activities as they had more resources to engage in those activities.

4.1 Limitations of the study

There are a number of limitations that may have affected the findings of this study, including number of respondents due to the medium of data collection. The virtual data collection was conducted in a short period, indicating a limited time frame that influenced the numbers of respondents. The data collected through an online platform was adopted during the movement control order enforced in Malaysia during that moment. Next, due to the lengthy process of answering the questionnaire, the study could not collect the amount of sample size due to noncompliance or limited time that they can be allocated to answer the questionnaire.

The limitations that the researcher have limited time also influenced the number of respondents (n=75). The researcher could not meet the respondents and explain the study face-to-face to convince the parents to participate in the study. The use of Google form to collect data also influenced the participation rate and result of the study due to the fact that the respondents could not analyze the result of the assessment after they finished answering the instrument.

The result of the study is also influenced by the questions related to the objectives of the study and the exact hypothesis could not be analyzed in the study. This is due to the fact that the test did not consider the fact that the parents are engaged in the activity previously or not, hence did not consider the activities that the parents enjoyed.

Future research should consider the instrument needed in order to collect data. The instrument should only focus on the results needed so that the results are not biased. A simple instrument is also good for the respondents so that the respondents can focus on giving the data needed to be part of the study. Other than that, future researchers can also focus on one disability, to gain the exact information needed for the study. Meanwhile, larger sample size is needed in order to enable the generalization of data to the targeted population.

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