Mothers of Autistic Children: Is the Burden of Care, Extended Time Spend and Money Constraints, Effecting Their Social Participation?

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ABSTRACT

Objectives: This study aimed to examine the relationship between caregiving for autistic children and their mothers' social participation. It also evaluated the effects of three factors; time, finances and stigma attached to the disability upon social participation. Methods: Purposive sampling technique was used to recruit mothers of autistic children living in Saudi Arabia. A survey was conducted to collect data from 42 mothers of children with autism. Ordinal regression was used to examine the relationship between the social participation of the mothers of autistic children and caregiving and the other factors. Descriptive statistics were used to analyse demographic data. Results: We found that caregiving for autistic children had a negative relationship with the amount of mothers’ social participation (significant at p<0.05). Moreover, social participation was affected negatively by factors such as time, finance and stigma. The most significant amongst them was time followed by financial constraints. Stigma was the least momentous factor. Conclusions: The social participation of mothers of autistic children in Saudi Arabia is negatively influenced by multidimensional and high care demands. This is further complicated by additional financial pressures, time constraints, and stigma associated with this disabling condition. Provision of a variety of social support programs and trainings, such as effective time management, adequate coping skills and counselling services may help in overcoming these obstacles. This in turn may aid not only in improving social participation, but also occupational balance, psychological wellbeing and quality of life of the effected mothers.

Keywords: autism, mothers, caregivers, social participation, occupations, and caregiving

1. INTRODUCTION

Autism Spectrum Disorders (ASD) is a group of disorders that is characterized by impairments in domains of communication, behavior and social interactions [1]. Disorders, such as autism, form complex and multidimensional challenges that can easily limit major activities of human life not only for the child, but also for the families especially mothers [2]. There is a decreased awareness about autism in the Kingdom of Saudi Arabia (KSA) [3] despite it being a rapidly growing developmental disability with a worrying growth rate of 11-16 per cent per annum since 1990’s.
In most instances, mothers are the primary caregivers of their autistic child and burden of care due to the nature of this illness might hamper their ability to engage in adequate Social Participation (SP). Also, they might feel guilty and blame themselves for their child’s condition resulting in getting depressed or anxious, resulting in a poorer quality of life and further decrease in socialization.

SP is defined as involvement of an individual in activities in order to provide connections with others in society [6]. It is a vital part of human experience that leads to life satisfaction and is essential for psychological, emotional and skills development. SP may include visiting friends, going shopping and other Social Activities (SA), but does not include talking to family members at home. Various studies around the globe including a few from Middle East have indicated that caring for autistic children restricts the mothers’ socialization and occupation as well as effects their quality of life owing to different reasons ranging from financial strains caused by the huge expenditure on medication and specialized care to experiencing stigmatization [2,7,8,9]. However, no research has been conducted in KSA specifically to explore this imperative issue and this is the first study aiming to evaluate the impact of caregiving on the SP of autistic children’s mothers.

The objectives of the study were:

- To find a relationship between the social participation of mothers of children with autism and caring for their children
- To find a relationship between the social participation of mothers of children with autism and time, finance and stigma

2. METHODS

It was a joint venture by the University of Brighton, UK and King Abdul Aziz Medical City (KAAMC) Riyadh, KSA. Approval was taken from ethical committees of both the institutions. Quantitative method using a survey was adopted and a purposive sample of mothers was recruited from KAAMC-Riyadh. Sample size was 37 participants.

Inclusion criteria were mothers who were Saudi nationals and were main carers. Exclusion were mothers who were receiving physical, mental or psychological treatment, because of possible effect on the mothers’ ability to care for their autistic children. All participants signed a consent sheet and an information sheet before data collection.

A structured questionnaire was developed for this purpose according to the needs and culture of the target population. Some items were taken from Life Participation Profile [10]. It was developed in English, translated into Arabic and back-translated into English. Then it was sent to a team of expert professionals at autism centre, Riyadh for content and quality review. It was checked for the accuracy of translation, wording and content, a minor modification was made and was approved for piloting.

Ten mothers were recruited from an autism centre for piloting the questionnaire after explaining the aim of the study to them. Participants spoke to the researcher via Skype and following a 15-minute description of the project, verbal consent was obtained, and they were asked to complete the questionnaire. On an average, most of them completed it between 8-10 minutes, whereas one mother took 17 minutes due to disruption by family members.

Few mothers cited a difficulty while answering the questions if they had to choose one option or more than one, because it was not specified how many factors they could choose. Thus, the questionnaire was modified, clarifying that they could choose all the factors that were applicable. After successful piloting, final questionnaire was used for study. Participants were allowed to complete it at home or during a clinical session at the hospital. It comprised of four parts:

I. Personal details like age, education, marital status, working hours and employment.

II. Questions to assess level of mothers’ SP to see how engaged they were in SA with their husbands, family, friends and the community.

III. Questions about care provided to the autistic children, subdivided in the categories of personal, physical, educational, social and health care.

IV. Questions about important factors like time, finance and stigma.

The questionnaire consisted of forty statements, thirty-seven of which were closed, and the rest were open-ended. The Likert Scale was used to measure mothers’ participation in SA.

The questionnaire was then distributed to 80 participants after taking written informed consent. The questionnaire took 10 minutes on average to complete. Participants’ data was kept in a safe place to protect their confidentiality.
The Software Package for Social Science (version 21) was used for data entry and analysis. The options under each statement were given a score. Any unanswered question was scored -999. Manual coding was used to categorize answers in groups according to the nature of answers. Frequencies and percentages were calculated for the quantitative data. For inferential analysis, ordinal regression was used to examine the relationship between the SP of the mothers of autistic children and caregiving and the other factors (time, finance and stigma). Value of p less than 0.05 was considered significant statistically.

3. RESULTS

Response rate was 72.50% where 58/ 80 participants returned the questionnaire. Out of these, 16 were excluded as they were either incomplete or incorrectly completed. Consequently, 42 questionnaires were analyzed for results.

Mean age of the participants was 27.40 years (SD=.497); 28.00% of mothers were aged 20-29 and 69.00% of them were aged 30-39 whereas 3.00% of them were aged 40-49. About 4.80% of mothers were widows, 7.10% were separated and 88.10% were married.

Percentage of uneducated mothers was 7.15%. 19.00% of them had secondary education, 9.53% had passed elementary school and 64.32% had achieved higher education. 42.90% of mothers were employed. A small number of employed participants, about 15.80%, worked less than 6 hours, 52.60% of them worked more than 6 hours and 31.60% worked more than 9 hours.

Regarding income, 38.10% of respondents had no income, 2.40% earned less than $800 (3,000SR), 14.30% earned between $800-$1600 (3,000-6,000 SR), 21.40% earned between $1600-$2400 (6,000-9,000 SR) and 23.80% earned between $2400-$3200 (9,000-12,000 SR).

The majority (57.10%) of mothers reported that time constraints were the major issue effecting their SP, whereas 28.60% mothers cited financial circumstances as main cause. Only 14.30% of mothers reported stigma as the issue that constrained them from SP (Table 1).

Table 1: Factors affecting social participation

<table>
<thead>
<tr>
<th>Valid</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time constraint</td>
<td>24</td>
<td>57.10</td>
<td>57.10</td>
<td>57.10</td>
</tr>
<tr>
<td>Financial situation</td>
<td>12</td>
<td>28.60</td>
<td>28.60</td>
<td>85.70</td>
</tr>
<tr>
<td>Stigma</td>
<td>6</td>
<td>14.30</td>
<td>14.30</td>
<td>100.00</td>
</tr>
<tr>
<td>Total</td>
<td>42</td>
<td>100.0</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>

In response to the statement: “I do not feel stigmatized when I go out with my autistic child” majority of mothers (57.10%) agreed while still a large number disagreed saying that they did feel stigmatized.

The majority of participants disagreed that they had enough time to participate in SA. Individual domains of SP are discussed in Table 2. Nearly 42.88% of mothers never participated in SA with friends; 35.68% spent 4 hours or less a month, 16.67% spent 4 hours or more a month and 4.77% reported that they spent 8 hours or more a month doing so. About 27.60% and 31.00% of mothers strongly agreed or agreed that they had time to fulfil their children’s personal and physical needs whereas 21.50% of mothers reported otherwise.

Table 2: Mothers' social participation

<table>
<thead>
<tr>
<th></th>
<th>Few times/year</th>
<th>Few times/month</th>
<th>Once more/week</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>1- I visit my family</td>
<td>26.20%</td>
<td>35.70%</td>
<td>38.10%</td>
<td>-</td>
</tr>
<tr>
<td>2- I visit my friends</td>
<td>52.20%</td>
<td>33.20%</td>
<td>7.13%</td>
<td>7.13%</td>
</tr>
<tr>
<td>3- I often go to a café or restaurant with my husband, family or friends.</td>
<td>45.20%</td>
<td>42.90%</td>
<td>11.90%</td>
<td>-</td>
</tr>
</tbody>
</table>
Regarding caring of child provided by mother, breakdown of activities and level of dependency of child is given in table 3. The majority of participants 96.16% and 95.20% strongly agreed/agreed giving a bath and arranging medical services for their children respectively whereas 2.40% disagreed/strongly disagreed.

About 58.00% of mothers reported that they spent more than 6 hours caring for their child, 22.00% spent 4-6 hours, 18.00% spent 2-4 and about 2.00% spent less than 2 hours (Figure 1).

Table 3: Caring for my child

<table>
<thead>
<tr>
<th>Activity</th>
<th>Agree + strongly</th>
<th>Disagree + strongly</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>1- I am main carer for my child.</td>
<td>100.00%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>2- I help my child to eat</td>
<td>100.00%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>3- I help my child to drink</td>
<td>66.70%</td>
<td>30.90%</td>
<td>2.40</td>
</tr>
<tr>
<td>4- I help my child with his/her toileting</td>
<td>90.50%</td>
<td>9.50%</td>
<td>-</td>
</tr>
<tr>
<td>5- I help my child to have a bath</td>
<td>96.16%</td>
<td>2.40%</td>
<td>1.44%</td>
</tr>
<tr>
<td>6- I help my child to dress</td>
<td>90.50%</td>
<td>9.50%</td>
<td>-</td>
</tr>
<tr>
<td>7- I regularly meet my child’s teachers.</td>
<td>71.50%</td>
<td>4.70%</td>
<td>23.80%</td>
</tr>
<tr>
<td>8- I teach my child and help him/her with homework</td>
<td>76.20%</td>
<td>-</td>
<td>23.80</td>
</tr>
<tr>
<td>9- I help my child to join social activities (e.g. going to special needs leisure center).</td>
<td>61.90%</td>
<td>19.05%</td>
<td>19.05%</td>
</tr>
<tr>
<td>10- I arrange health services for my child (e.g. hospital appointments, attending treatment sessions).</td>
<td>95.20%</td>
<td>2.40%</td>
<td>2.40%</td>
</tr>
</tbody>
</table>
Ordinal regression analysis showed that there was a negative relationship between the mothers’ SP and caring for their children, the P value being estimated at -0.037 and significant at P<0.05.

Findings also suggested that time constraints, financial situation and stigma had negative estimates (-2.870, -1.008, -0.109 respectively) which were significant at P<0.05 except stigma that was not significant at P<0.05 (estimated at 2.359). Most mothers (68.00%) affirmed that they had financial issues limiting their SP. In the open question regarding factors other than those in questionnaire, 27.00% of mothers reported that their child’s behaviour negatively influenced their SP, while 9.10% held their child’s routine to be responsible for that.

4. DISCUSSION

This study aimed at targeting the important issue of diminished SP mothers of autistic children as a result of caregiving for their children. Most of the participants were married with a mean age of 27.40 years, which contrasted the previous study in Taiwan (9). Shu found that the mean age of mothers was 49 years. The younger age of mothers in our sample can however be explained in the sociocultural context of KSA where usually girls would get married at a younger age.

Majority of mothers were educated, and this was in line with the finding of the studies done in Taiwan and Qatar [8,9]. Unemployment rate was found to be higher (57.10%) in our study and it is in line with other studies that reported better percentage of employment [7,8]. This could be explained by the lack of services like carers and caring centers for children with disabilities in individual countries like KSA that might enable the mothers of these children to work [8].

Regarding working hours, we found that 52.60% mothers worked for more than 6 hours/ day while 15.80% worked for less than 6 hours. Various other studies cited similar findings that most mothers of disabled children worked 30 hours or more/ week [11]. Working long hours might be dependent on amount of salary and condition of child. If paid handsomely, mothers tended to work longer hours as they thought they could spend that money on child’s special needs and compensate for the time spent away from them. Similarly, if the child was stable, the mother did not mind working for long hours [11]. Absence of a flexible working hours’ system in KSA for these mothers might be a reason of their long working hours and unemployment.

The main finding of our study was that a negative relationship existed between mothers' SP and caregiving for their autistic children. This indicates that mothers who provide more care for their children seem to be participating less in SA. These findings support previous studies [10,12], which found that caring for autistic children restricted mothers from socializing in different activities, such as meeting friends/ family and going on holidays.

However, there were contradictory findings from other researches [13] stating that there was no difference in SP between mothers who care for disabled children and mothers who care for typical children. A possible reason could be that children in that study were in school age. Children who spend a big chunk of their day away from home leave more time for their mother to participate in SA. Additionally, school age children are usually better in self-care activities like eating and drinking. However, our study included mothers whose children were from all age groups.

We tried to explore any relationship between participation of mothers in SA and factors like time, finance and stigma as well. We found that time was the most constraining factor limiting the SP of mothers of autistic children, as reported by 57.10% of mothers. Interestingly, mothers reported spending less time on children’s leisure activities. This could be because of lack of provision of such resources for disabled children in the kingdom. In fact, in the survey done by Dyches et al, 70% of parents had already expressed a dire need for recreational activities for their disabled children [14].

Majority of mothers (52.60%) in this study reported spending more than 6 hours a day on activities related to personal and physical needs of children like eating, dressing, toileting, bathing and arranging for health services. These findings were in line with previous researches [7,17], which found that mothers having children disabilities spent significant hours per day taking care of their children and spent less time on other activities, such as SA, compared to mothers with children without disabilities. Mothers in our study cited financial challenges to be a major factor leading to their decreased participation in SA. A previous study has demonstrated that financial problems in such families has a link with extra expenses involved in tending to special needs of the child [16]. This restricts the family from participation in everyday occupation, such as social events (attending birthdays), leisure pursuits (relaxation) and productive activities (employment) [15]. As a result, mothers preferred spending money on their children’s needs rather than on their own social needs, such as eating with friends and/or family at restaurants. Paradoxically, there might be families with no financial difficulties but still less SP because mothers might be working longer hours to earn enough money at the cost of time they could have spent with their children or in socializing. Both time constraints and lack of finances increase the mothers’ inability to participate in meaningful SA and may result in isolation and reduced psychological wellbeing [16]. This may create a high-stress environment for them at home [17] and the much-needed SP, which could alleviate some of the effects of this, would remain inaccessible. This study also implies that mothers who felt stigmatized, participated less in SA. Previous studies mirrored these findings [18,19] and agreed that such mothers tended not to socialize due to stigma and common social rejection. They also experienced limited participation in social occupations, such as attending parties, visiting friends and going out to public places [19]. Earlier studies have postulated other possible reasons like dealing with challenging behavior of child and not only stigma to be causing decreased socialization [14]. This supports our findings, which suggest that SP of mothers is partially affected by their child’s behavior and routines, but it may not be a major factor that effects Saudi mothers’ SP. Another possible reason could be that most of the participants had spent significant amount of time in developed countries, such as UK and US. In past ten years, Saudi government has sent many students on scholarships and many of these mothers had benefitted from this scheme. Living in more developed countries might have improved their attitude and reduced feelings of guilt and shame associated with taking out their special child to public place. Looking more closely now at the impact of caring for autistic children on their mothers’ SP, it seems that less socialization may lead mothers to be socially excluded which may negatively affect their mental health and psychological wellbeing. As discussed, participation in occupations, such as SA is a vital part of human condition and experience and it leads to life satisfaction and is essential for psychological, emotional and skills development. It is found that the increased responsibilities of caring for a child with autism resulted in social isolation of mothers, placing them at a higher risk of experiencing mental health issues due to the stress of caring for their children [17]. There is a dire need to provide social support programs including training for time management and coping strategies, in order to improve mothers’ SP and might lead to better SA and everyday occupations, such as self-care and productivity. Additionally, there should be some form of health insurance to help decrease the financial burden of medical expenses and therapy costs. Educational programs should also be initiated in order to increase awareness in Saudi society regarding such disorders. This may help in reducing stigma in society attached to these disorders. Saudi occupational therapists should also work collaboratively with the mothers of autistic children to understand and gain a holistic picture of their occupational needs. This may then enable them to participate in everyday occupations, such as self-care, leisure and other productive activities, which they may wish to participate in. Participation in such occupations may improve not only their psychological wellbeing, but also their quality of life. Unfortunately, occupational therapy is a new field in KSA and there is lack of knowledge about it [20] so many of work needs to be done in order to bridge this knowledge gap and to educate the caregivers about available rehabilitation options like OT. Although this study provided significant findings about the SP of mothers of children with autism in KSA, there were several limitations. First, the children’s ages and the severity of their autism have not been considered in this study. This may affect the findings because it has been found that mothers of autistic children at school age and with mild autism have more time to engage in different activities than mothers of children less than 11 [13]. Moreover,

although a pilot study was done to ascertain the reliability of the questionnaire, the internal validity could not be determined using statistical tests due to the ordinal nature of the variables used. Lastly, this was not a multi-center study and when generalizing the results, it must be kept in consideration that it was conducted in a tertiary care hospital of the capital city. To build up a broader picture of the SP of mothers of autistic children in KSA at large, there would be a need to replicate such studies in various hospitals in other regions as well.

5. CONCLUSION

This quantitative study demonstrates that the SP of mothers of children with a developing disability, such as autism, is negatively affected by lack of time, social stigma and increased energy and resources spent on caring for these children in a developing country like KSA. Additionally, increased expenditure on caring for their autistic children hampers the mothers from spending more on SA. Active involvement of these mothers in training programs to cope effectively might improve the existing situation. Saudi occupational therapists might play an instrumental role by working collaboratively with the mothers to obtain a holistic picture of their occupational needs and thus find solutions to enable them to participate in meaningful and purposeful occupations in their everyday lives.

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CONFLICTING INTEREST

The research was conducted in part-fulfilment of MSc degree in Occupational Therapy from the University of Brighton in the United Kingdom.

REFERENCES
