Exploring the challenges and opportunities related to the quality of daily living among mothers of children with autism in Bangladesh

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Objective of the Study

- To explore mothers’ understanding about ‘autism’, find out the challenges and opportunities to perform activities of daily living considering physical, mental, family, and social wellbeing.
Background

• 1 in every 110 children are diagnosed as children with autism over the world. (Kopetz & Endowed, 2012)

• About 10.5 million children were diagnosed as autism in Bangladesh. (Rahman, 2010)

• Where about 76,000 children under the age of five years. (Khan, 2015)(Rakib, 2013).
Background

Quality of life (WHO)
- Physical Health
- Psychological Health
- Social Relations
- Environment

Mother of Children with Autism

Daily living Activities
- Taking care of child with autism
- Housekeeping
- Care to other family members
- Doing self-care, job and leisure

Well-being
Background

Special Rehabilitation Centers for Autism

Inclusive School

Mothers’ responsibilities

Care to other family members

Mother Social Time

- How about mothers’ daily living experiences?
- How about their health and well-being to participate in day to day?
Methods and Data Gathering

• Ethnographical Study

• Settings
  • Rehabilitation Centre, Centre for the Rehabilitation of the Paralysed (CRP)
  • Proyash Specialized School and Rehabilitation
  • Beautiful Mind – A Specialized Care for Children with Autism.

• Sampling:
  • Purposive sampling; Total (N= 10)

• Inclusion Criteria:
  • Mothers who were at least 18 - 50 years old.
  • At least completed primary education.
  • Have active communication abilities.
Methods and Data Gathering

• Procedure:
  – Semi-structured interview.
  – Open-ended.
  – Observation.
  – Each session: 70 – 90 minutes.
  – Field notes.

• Analysis:
  – Thematic analysis
## Results

<table>
<thead>
<tr>
<th>Mother (M)</th>
<th>Age</th>
<th>Living area</th>
<th>Educational background</th>
<th>Occupation</th>
<th>Child’s age</th>
<th>Number of child</th>
<th>Family Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>M-1</td>
<td>28</td>
<td>Urban</td>
<td>Graduate</td>
<td>Teacher</td>
<td>5 years</td>
<td>1</td>
<td>Nuclear family</td>
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<tr>
<td>M-2</td>
<td>34</td>
<td>Urban</td>
<td>Graduate</td>
<td>Accountant (Resigned)</td>
<td>6 years</td>
<td>2</td>
<td>Extended family</td>
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<tr>
<td>M-3</td>
<td>25</td>
<td>Rural</td>
<td>Primary Education completed</td>
<td>Housewife</td>
<td>10 years</td>
<td>2</td>
<td>Extended family</td>
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<td>M-4</td>
<td>33</td>
<td>Urban</td>
<td>Graduate</td>
<td>Housewife</td>
<td>7 years</td>
<td>3</td>
<td>Nuclear family</td>
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<tr>
<td>M-5</td>
<td>22</td>
<td>Semi-Urban</td>
<td>Secondary School completed</td>
<td>Teacher (Part-time)</td>
<td>4 years</td>
<td>1</td>
<td>Nuclear family</td>
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<td>M-6</td>
<td>40</td>
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<td>Graduate</td>
<td>Government job (Resign)</td>
<td>10 years</td>
<td>3</td>
<td>Extended family</td>
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<td>M-7</td>
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<td>Urban</td>
<td>Higher Secondary School completed</td>
<td>Housewife</td>
<td>6 years</td>
<td>2</td>
<td>Nuclear family</td>
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<td>M-8</td>
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<td>Semi-urban</td>
<td>Higher Secondary School completed</td>
<td>Housewife</td>
<td>6 years</td>
<td>3</td>
<td>Extended family</td>
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<td>M-9</td>
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<td>Urban</td>
<td>Graduate</td>
<td>Discontinuing job</td>
<td>17 years</td>
<td>3</td>
<td>Nuclear family</td>
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<tr>
<td>M-10</td>
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<td>Urban</td>
<td>Post-Graduate</td>
<td>Lawyer</td>
<td>15 years</td>
<td>2</td>
<td>Extended family</td>
</tr>
</tbody>
</table>
Figure 1: mothers’ time-use percentages in daily living activities
Limited understanding about ‘autism’ and its consequences

Frequent physical complication protest to perform daily activities

Imbalanced occupational life

Feeling of guiltiness and frustration destroy desires gradually

Family members are always supportive but negative attitudes comes from society

5/23/2018
Discussion

Mothers' educational program to balance occupations

- Limited understanding about ‘autism’ and its impact
- Imbalanced occupational life

Innovative and comprehensive community based program

- Frequent physical complication protest to perform daily activities
- Feeling of guilty and frustration destroyed gradually
- Family members are supportive rather than negative attitude comes from society
Discussion

Public education

Publicity

Knowledge about autism

Rehabilitation follow-up

Prioritizing activities

Mothers’ educational program to balance daily occupations

Balanced life

5/23/2018
Discussion

Advance treatment

Positive attitudes

Home based program

Inclusive society

Innovative and comprehensive community based program
Conclusion

• Supports from family members is most efficient resource to lead a quality of daily living.

• Need advance care and home based Occupational consultancy to promote health and well-being.
THANK YOU for your ATTENTION!
Reference List


