The experiences impacting on the Quality of Life of mothers of children with intellectual disability and autism spectrum disorder: a qualitative study

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Overview

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- Aims
- Methods
- Results
- Summary
Introduction

- Quality of Life (QoL), autism spectrum disorder (autism), intellectual disability (ID) & comorbid autism
- No. of mothers caring for a child with ID & autism
- Lower QoL in mothers of children with ID & mothers of children with autism
- No published research on QoL has separated the mothers of children with both ID & autism from mothers of children with autism only.

Our aims

• To explore QoL in mothers of children with ID & autism

• To identify the factors impacting on their QoL

• To document supports which improved these mothers’ QoL & their suggestions for such supports
Methods

- Qualitative study (interpretive phenomenology) with recruitment via Autism Association of WA
- Audio-taped interviews of mothers of 11-24 year olds with ID & autism
- Open-ended questions in mother’s home/work-place or researcher’s work-place
- Interviews were transcribed & analysed thematically for the essence of their lived experience
Participants (n=16)

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Maternal age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td>40-44 years</td>
</tr>
<tr>
<td>Married</td>
<td>45-49 years</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>No. of children with a disability in mother’s care</th>
<th>Employment status</th>
<th>Family SES</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 child</td>
<td>employed</td>
<td>High</td>
</tr>
<tr>
<td>2 children</td>
<td>unemployed</td>
<td>Upper middle</td>
</tr>
<tr>
<td>3 children</td>
<td></td>
<td>Lower middle</td>
</tr>
</tbody>
</table>

SES, socio-economic status; * Index child is the child with ID & autism.
Index children (n=17)

- 12 males & 5 females
- 11-24 years
- 9 were assessed as low functioning, 4 medium & 4 high
- 6 of the children lived in full-time care at the time of interview
Part A: The themes

1. Coping with aspects of the child’s disability

2. Adapting to new boundaries

3. Surviving the challenges & savouring the rewards
1. Coping with aspects of the disability

*Challenging behaviours* were cited most often as reducing a mother’s QoL.

Here, the most commonly described behaviours were:

- Running away (7 children)
- Screaming & tantrums (6 children)
- Violence (5 children)
2. Adapting to new boundaries

Common areas of challenge were:

- Future plans (10 mothers)
- Increased demands (10 mothers)
- Loss of leisure (9 mothers)
3. Surviving the challenges

Common challenges related to:

- Employment (11 mothers)
- Health (9 mothers)
- Relationships (all mothers)

3 mothers expressed prior thoughts of suicide.
And savouring the rewards

Mothers described rewards in 5 areas pertaining to:

1. Their love for the child (14 mothers)
2. Personal development (5 mothers)
3. Child development (3 mothers)
4. Meeting exceptional people (7 mothers)
5. Appreciating simple things (4 mothers)
Part B: Improving QoL

- Meditation courses
- Mentor angels
- Comprehensive sitter services
- Agency initiated phone calls
- More respite for parents of adult children
- Provision of a service directory at diagnosis
Mothers associated their QoL with:

- Coping with difficult disability traits
- Adapting to new boundaries such as a revised future
- Surviving detriments to their employment, health & relationships

Mothers savoured rewards & suggested ways to improve QoL in mothers of children with ID & autism.
Acknowledgements

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Any questions?