Interventions on Psychological Well-being of Parents having Children with ASD: Insights from a Systematic Review

Unpublished findings. Should you wish to quote any of the findings, please contact Dr. Paul Wong at paulw@hku.hk

*Dr. Samantha Wong, *Ms. Suet-ying Yuen, Dr. Paul Wong, Mr. Ryan Chan, Ms. Wylie Li, Ms. Karine Ngai, & Dr. Sandra Tsang

JC A-Connect (Family Support), The University of Hong Kong
Hong Kong ASD Conference 2017: Family Support and Development
Parallel Symposia – Symposium II, January 9, 2017
Systematic Review

Levels of evidence pyramid
Aims

1. Present **findings** from the systematic review
2. Highlight the **importance and effective intervention elements** on psychological well-being of parents having children with Autism Spectrum Disorder (ASD)
3. Discuss **implications** for practice and research
Outline

1. Background
2. Method
3. Results
4. Our observations
5. Implications
1. Background
Background

1. Rising prevalence of ASD in global and local context
2. Emerging concerns on parents’ psychological well-being
3. Limited interventions for families having children with ASD


2. Objectives and research questions
2.1 Objectives

1. Summarize existing studies
2. Evaluate methodological quality
3. Synthesize major findings
4. Identify intervention elements
2.2 Research questions

1. What were the **methodological qualities** of the existing interventions for parents having children with ASD, targeting on their psychological well-being?

2. How were these interventions being **evaluated**?

3. What **outcomes** were reported on parents’ psychological well-being?

4. What were the commonly used **intervention elements** among these studies?
3. Method
3.1 Established guideline for review

Protocol for systematic review

Built according to the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) 2015 statement (Mohor et al., 2015)
3.2 Keywords & selection criteria

Combination of search terms

- "autis*" OR "ASD"
- AND
- "parent*" OR "family"
- AND
- "support*" OR "service*"
- OR "intervention*

In 11 electronic databases

Selection Criteria

Inclusion criteria
1. Peer-reviewed journal articles
2. Full-text available
3. Written in English
4. Interventions for parents of children with ASD
5. With measurable outcomes

Exclusion criteria
1. Review/ systematic review articles
2. Letter or commentary paper
3. Non-intervention studies
3.3 Quality assessment & data analysis

Assessment on reporting quality

- **Quality assessment checklists**
  - CONSORT 2010 statement (Schulz et al., 2010) → RCTs
  - TREND statement (Des Jarlais et al., 2004) → Non-RCT studies
  - SRQR (O’Brien et al., 2014) → Mixed-design studies
  - Qualitative studies

Data extraction and analysis method

1. Two-phase convergent qualitative synthesis
2. Thematic synthesis
4. Results
4.1 Flow of study selection
4.2 Appraisal on reporting quality

Quality assessment checklists

- CONSORT 2010 statement
  (Schulz et al., 2010)
  - RCTs (n=4)
    Score: 19-28/37

- TREND statement
  (Des Jarlais et al., 2004)
  - Non-RCT studies (n=18)
    Score: 19-40/57
  - Mixed-design studies (n=6)
    Score: 16-41/57

- SRQR
  (O’Brien et al., 2014)
  - Qualitative studies (n=3)
    Score: 12-21/21
4.3 Description of studies (n=31)

1. Publication year
   - 17 of them published within 2011-2016

2. Country
   - The United States, 12
   - Australia, 6
   - United Kingdom, 3
   - Canada, 2
   - Jordan, 2
   - China, 2
   - Iran, 1
   - Turkey, 1
   - Taiwan, 1
   - India, 1
   - The United States, 12
4.3 Description of studies - *Participants*

1. Total no. of participants included = **1,250** (mothers only, mother/father, couples, grandparents, or other caregivers)

2. Sample size varies from **3** to **122**

3. Children in different stages
4.3 Description of studies – *Programme delivery*

According to the **National Institute for Clinical Excellence (NICE) guideline** *(National Institute for Clinical Excellence, 2006; Small et al., 2009)* and review studies on **parent education programmes** *(Lang et al., 2009; Dababnah & Parish, 2016)*:

<table>
<thead>
<tr>
<th>Group-based intervention</th>
<th>Intervention with established protocols</th>
<th>Intervention with fidelity check</th>
<th>Intervention with follow-up evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>n=17</td>
<td>n=18</td>
<td>n=7</td>
<td>n=10</td>
</tr>
</tbody>
</table>

Follow-ups vary from 1 month to 1 year
4.3 Description of studies – Scope of measurements

1. **39 different measures applied**
2. 9 measure **domains included**

<table>
<thead>
<tr>
<th>Measure domain</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Coping</td>
</tr>
<tr>
<td>2. General health</td>
</tr>
<tr>
<td>3. Family functioning</td>
</tr>
<tr>
<td>4. Parental perception</td>
</tr>
<tr>
<td>5. Self-efficacy</td>
</tr>
<tr>
<td>6. Quality of life</td>
</tr>
<tr>
<td>7. Positive affect</td>
</tr>
<tr>
<td>8. Distress</td>
</tr>
<tr>
<td>9. Psychological disturbance</td>
</tr>
</tbody>
</table>
4.4 Intervention effectiveness – *Positive qualities*

1. **Significant improvements** on *positive* qualities:
   
a) Coping (n=7)
   
b) Self-efficacy (n=7)
   
c) General health (n=5)
   
d) Family functioning (n=4)
   
e) Parental perceptions (n=1)
   
f) Quality of life (n=1)
   
g) Affect (n=1)

2. **No significant outcomes:** 5 studies
4.4 Intervention effectiveness – Negative qualities

1. Significant reductions on negative qualities:
   a) Distress (n=15)
   b) Psychological disturbance (n=4)

2. No significant outcomes: 4 studies
### 4.5 Themes of intervention elements

All **28 effective** studies

<table>
<thead>
<tr>
<th>Theme</th>
<th>Intervention element</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD general information (n=11)</td>
<td>ASD knowledge (n=6)</td>
</tr>
<tr>
<td></td>
<td>ASD information (n=5)</td>
</tr>
<tr>
<td>ASD-specific skill training (n=24)</td>
<td>Social communication intervention (n=5)</td>
</tr>
<tr>
<td></td>
<td>Behavioral learning (n=4)</td>
</tr>
<tr>
<td></td>
<td>Behavioral management (n=11)</td>
</tr>
<tr>
<td></td>
<td>Problem-solving training (n=3)</td>
</tr>
<tr>
<td></td>
<td>Cognitive behavioral intervention (n=1)</td>
</tr>
<tr>
<td>Parenting skill training (n=3)</td>
<td>Parenting intervention (n=3)</td>
</tr>
<tr>
<td>Parent psychological support (n=8)</td>
<td>Cognitive and emotional adjustment (n=1)</td>
</tr>
<tr>
<td></td>
<td>Psychological support (n=4)</td>
</tr>
<tr>
<td></td>
<td>Stress management (n=2)</td>
</tr>
<tr>
<td></td>
<td>Mutual support (n=1)</td>
</tr>
<tr>
<td>Family leisure (n=1)</td>
<td>Family leisure (n=1)</td>
</tr>
<tr>
<td>Community understanding (n=2)</td>
<td>Public awareness (n=2)</td>
</tr>
</tbody>
</table>
### 4.5 Themes of intervention elements – Age-specific 1

1. Newly diagnosed group (n=4)

<table>
<thead>
<tr>
<th>Theme</th>
<th>Intervention element</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD general information (n=3)</td>
<td>ASD knowledge (n=1)</td>
</tr>
<tr>
<td></td>
<td>ASD information (n=2)</td>
</tr>
<tr>
<td>ASD-specific skill training (n=3)</td>
<td>Social communication intervention (n=1)</td>
</tr>
<tr>
<td></td>
<td>Problem-solving training (n=2)</td>
</tr>
<tr>
<td>Parent psychological support (n=1)</td>
<td>Mutual support (n=1)</td>
</tr>
</tbody>
</table>
## 4.5 Themes of intervention elements – *Age-specific 2*

### 2. Preschool group (n=6)

<table>
<thead>
<tr>
<th>Theme</th>
<th>Intervention element</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD general information (n=3)</td>
<td>ASD knowledge (n=2)</td>
</tr>
<tr>
<td></td>
<td>ASD information (n=1)</td>
</tr>
<tr>
<td>ASD-specific skill training (n=9)</td>
<td>Social communication intervention (n=2)</td>
</tr>
<tr>
<td></td>
<td>Behavioral learning (n=3)</td>
</tr>
<tr>
<td></td>
<td>Behavioral management (n=3)</td>
</tr>
<tr>
<td></td>
<td>Problem-solving training (n=1)</td>
</tr>
<tr>
<td>Parent psychological support (n=3)</td>
<td>Psychological support (n=1)</td>
</tr>
<tr>
<td></td>
<td>Stress management (n=2)</td>
</tr>
<tr>
<td>Community understanding (n=1)</td>
<td>Public awareness (n=1)</td>
</tr>
</tbody>
</table>
### 4.5 Themes of intervention elements – Age-specific 3

#### 3. Across age groups (n=6)

<table>
<thead>
<tr>
<th>Theme</th>
<th>Intervention element</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD general information (n=4)</td>
<td>ASD knowledge (n=2)</td>
</tr>
<tr>
<td></td>
<td>ASD information (n=2)</td>
</tr>
<tr>
<td>ASD-specific skill training (n=2)</td>
<td>Behavioral management (n=1)</td>
</tr>
<tr>
<td></td>
<td>Cognitive behavioral intervention (n=1)</td>
</tr>
<tr>
<td>Parent psychological support (n=1)</td>
<td>Psychological support (n=1)</td>
</tr>
<tr>
<td>Family leisure (n=1)</td>
<td>Family leisure (n=1)</td>
</tr>
<tr>
<td>Community understanding (n=2)</td>
<td>Public awareness (n=2)</td>
</tr>
</tbody>
</table>
4.5 Themes of intervention elements – Mode of intervention 1

1. Individual-based studies (n=9)

<table>
<thead>
<tr>
<th>Theme</th>
<th>Intervention element</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD-specific skill training (n=11)</td>
<td>Social communication intervention (n=2)</td>
</tr>
<tr>
<td></td>
<td>Behavioral learning (n=4)</td>
</tr>
<tr>
<td></td>
<td>Behavioral management (n=3)</td>
</tr>
<tr>
<td></td>
<td>Problem-solving training (n=2)</td>
</tr>
<tr>
<td>Parenting skill training (n=2)</td>
<td>Parenting intervention (n=2)</td>
</tr>
</tbody>
</table>
### 4.5 Themes of intervention elements – Mode of intervention 2

#### 2. Group-based studies

<table>
<thead>
<tr>
<th>Theme</th>
<th>Intervention element</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD general information (n=7)</td>
<td>ASD knowledge (n=4)</td>
</tr>
<tr>
<td></td>
<td>ASD information (n=3)</td>
</tr>
<tr>
<td>ASD-specific skill training (n=11)</td>
<td>Social communication intervention (n=2)</td>
</tr>
<tr>
<td></td>
<td>Behavioral management (n=7)</td>
</tr>
<tr>
<td></td>
<td>Problem-solving training (n=1)</td>
</tr>
<tr>
<td></td>
<td>Cognitive behavioral intervention (n=1)</td>
</tr>
<tr>
<td>Parenting skill training (n=3)</td>
<td>Parenting intervention (n=3)</td>
</tr>
<tr>
<td>Parent psychological support (n=6)</td>
<td>Cognitive and emotional adjustment (n=1)</td>
</tr>
<tr>
<td></td>
<td>Psychological support (n=3)</td>
</tr>
<tr>
<td></td>
<td>Stress management (n=1)</td>
</tr>
<tr>
<td></td>
<td>Mutual support (n=1)</td>
</tr>
<tr>
<td>Family leisure (n=1)</td>
<td>Family leisure (n=1)</td>
</tr>
<tr>
<td>Community understanding (n=1)</td>
<td>Public awareness (n=1)</td>
</tr>
</tbody>
</table>
5. Observations
Observations

1. Growing attention on parent’s psychological well-being
2. Various reporting quality and evidence level of interventions
3. Various sample size and characteristics
4. Heterogeneous outcomes on psychological well-being
5. Increasing intervention elements associated with positive psychological well-being qualities
6. Limitations
Limitations

1. Various child’s factors (e.g. the severity of disorder, developmental stage, level of functioning)
2. Various parent’s factors (e.g. individual demographic variables, socioeconomic status)
3. Review restricted to English publications
7. Implications
7.1 Implications – Theory & Research

**Theory**

1. Examine the adaptation of theory into practice
   -> **The Double ABCX model** on family stress

2. Explore wider scope of theory on strength-based intervention
   -> **The Family Adjustment and Adaptation Response (FAAR) model** on family resilience

**Research**

1. Develop more rigorous studies for evidence-based interventions

2. Encourage a paradigm shift from child-centred to family-centred support

The A-POWER family support framework
7.2 Implications – Practice & Policy

**Practice**
1. Understand **different intervention elements** for future service development
2. Develop **age-specific** and **gender-specific** interventions
3. Develop interventions for parents with **elder child**, according to the research and service cliff

**Policy**
1. Compare global and local **policy** (US, Australia, low-resource setting countries and Hong Kong) and interventions developed
8. Recommendations
Recommendations

1. Increase **attention** on interventions targeting parent’s psychological well-being
   - Cognitive Behavioral Therapy (CBT) parents groups

2. Develop more rigorous **research design** and better **reporting quality** of intervention outcomes
   - Dissemination and sustainability of effective practices

3. Increase diversity on **intervention elements** for holistic family support
   - Age-specific, gender-specific and role-specific interventions

4. **Transfer knowledge** from global to local context
Key references


Thank you