SCALES USED FOR STRESS AND ANXIETY IN PARENTS OF CHILDREN WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES: SYSTEMATIC REVIEW

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WHEN?
- When a lot of evidence exists which needs to be analyzed and summarized.

USEFULNESS
- Inform medical recommendations, policy guidelines, new research


Image: https://kib.ki.se/en/search-evaluate/systematic-reviews
EXPLICIT METHODS OF A SYSTEMATIC REVIEW

1. Formulate the review question & write a protocol
2. Search for and include primary studies
3. Assess study quality
4. Extract data
5. Analyze data
6. Interpret results & write a report
BACKGROUND

- Increasing population with IDD
- Higher parental stress & anxiety
- Linked lives of parent & child
- Poor outcomes for parents
- Adverse impact on child with IDD

Brault, 2012; Gallagher, Phillips, Oliver, & Carroll, 2008; Piven et al., 1991; Barker et al., 2011; Dardas & Ahmad, 2014; Falk, Norris, & Quinn, 2014; Moore & Symons, 2009
To improve health outcomes for families and child with IDD

Need to use scales which assess stress and anxiety accurately

What measures of stress and anxiety have been used with parents of children with intellectual and developmental disability?
METHODS

- Protocol with specific inclusion and exclusion criteria, limits bias
- PRISMA guidelines, comprehensive methodology
- Risk of bias assessment for individual studies (Newcastle Ottawa Scales), limits bias in interpretation
- Medline (Mesh terms), gray literature, clinical trial registry, reference lists
RESULTS:
PRISMA Flowchart
RESULTS: OVERVIEW

Studies conducted 2003-2017

Conducted across the world: 9 countries and 1 study recruited internationally

Sample size range from 36 to 479

12 cross-sectional and 1 cohort study

69% of studies on parents of children with ASD, 31% on other ID

9 scales identified
RESULTS
QUALITY ASSESSMENT WITHIN STUDIES

Potential for selection bias
Heterogeneity
Indirectness
Publication bias

Good quality: 4 studies 31%
Fair quality: 5 studies 38%
Poor quality: 4 studies 31%
9 scales:

- 5 assessed only anxiety
- 2 assessed only stress
- 2 assessed both anxiety and stress

- The Parenting Stress Index (Short Form/Chinese) – 3 PSI/PSI-SF
- Hospital Anxiety and Depression Scale – 3 HADS
- Depression Anxiety Stress Scale (21/Arabic/Chinese) 4 DASS/DASS-21

Most frequently utilized scales in systematic review
The Parenting Stress Index-Short Form (PSI-SF)

- Used by 3 studies in this review
- Psychometrically assessed in 3 studies (Zaidman-Zait et. al, 2010, Zaidman-Zait et. al, 2011 and Dardas et. al, 2014)
- Samadi et. al (2014) used this scale but did not cite its additional psychometric properties as found by Zaidman-Zait et. al (2010, 2011). 7 additional studies conducted after initial publication.

Questionnaire on Resources and Stress – Short Form (QRS-F)

- Not used by any study in this review
- Psychometrically assessed in one paper by Honey et. al (2005). 12 studies conducted after publication of this paper.
DISCUSSION & THE ‘SO WHAT’

What criteria are researchers using to identify a scale to be used in their study?

- Popularity of scale
- *Ease of use*
- Appropriateness of constructs within scale
- *Age of child with IDD*
- Validity with study population

Are these choices leading to the correct diagnosis of stress and anxiety?
LIMITATIONS OF STUDY

- One reviewer
- One database
- No table of contents of high yield journals
- No annual conference abstracts
Assessing stress and anxiety amongst parents of children with IDD is crucial.

However, necessary that studies are using appropriate scales which have been selected purposefully.

Future studies should ensure that these reasons are explicitly stated and additional psychometric properties are examined.

Personally, will continue this review with other databases to determine final results.
Thank You!
Questions?
UNDERSTANDING THE RELATIONSHIP BETWEEN NUMBER OF DISABILITY RELATED CONDITIONS AND STIGMA AMONG ADULTS IN THE US

Chandra A. Char MPH
PhD student
Research question

- What is the relationship between number of disability related conditions and stigma?
Study purpose

• Examine the relationship between number of disability related conditions and stigma with identifying as a person with a disability, noticeability, and gender as moderators.
Data Set

- Disability Health Identity Survey
- Collected in 2017
- N=979, n=711
Methods

• **Modifiers:**
  - Gender
  - Identifying as a person with a disability
  - Noticeability

• **Covariates:**
  - Age
  - Education
  - Race
  - income

• Mechanical Turk (MTturk) via Amazon
• 8-item Stigma Scale for Chronic Illness
• Theory: Stigma Theory (Goffman, 1963)
Analysis

• R version 3.5
• Multiple Linear Regression
  • Backwards stepwise elimination
• Comparison of means
## Results: Bivariate Statistics

<table>
<thead>
<tr>
<th>Variable</th>
<th>N(%)</th>
<th>Mean value of stigma</th>
<th>SD</th>
<th>Unadjusted P-values</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>male</td>
<td>391 (55)</td>
<td>14.7</td>
<td>6.82</td>
<td></td>
</tr>
<tr>
<td>female</td>
<td>314 (44)</td>
<td>14.1</td>
<td>6.71</td>
<td></td>
</tr>
<tr>
<td>Non-binary</td>
<td>6 (0.84)</td>
<td>15.7</td>
<td>9.05</td>
<td></td>
</tr>
<tr>
<td><strong>Identify as a person with a disability</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strongly Agree</td>
<td>20 (2.8)</td>
<td>22.3</td>
<td>9.66</td>
<td></td>
</tr>
<tr>
<td>Agree</td>
<td>61 (8.6)</td>
<td>20.8</td>
<td>6.46</td>
<td></td>
</tr>
<tr>
<td>Neutral</td>
<td>56 (7.9)</td>
<td>18.9</td>
<td>6.91</td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>193 (27.1)</td>
<td>16.2</td>
<td>6.48</td>
<td></td>
</tr>
<tr>
<td>Strongly Disagree</td>
<td>381 (53.6)</td>
<td>11.4</td>
<td>4.79</td>
<td></td>
</tr>
<tr>
<td><strong>Noticeability</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strongly Agree</td>
<td>63 (8.8)</td>
<td>20.6</td>
<td>8.0</td>
<td></td>
</tr>
<tr>
<td>Agree</td>
<td>129 (18.1)</td>
<td>18.3</td>
<td>7.42</td>
<td></td>
</tr>
<tr>
<td>Neutral</td>
<td>252 (35.4)</td>
<td>14.0</td>
<td>5.78</td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>169 (23.7)</td>
<td>12.2</td>
<td>5.26</td>
<td></td>
</tr>
<tr>
<td>Strongly Disagree (1)</td>
<td>98 (13.78)</td>
<td>10.2</td>
<td>3.97</td>
<td></td>
</tr>
</tbody>
</table>
## Multilinear Regression

<table>
<thead>
<tr>
<th>Variable</th>
<th>Estimate</th>
<th>Confidence Interval</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male to non-binary</td>
<td>1.198</td>
<td>[-2.908, 5.303]</td>
<td>0.567</td>
</tr>
<tr>
<td>Female to non-binary</td>
<td>0.668</td>
<td>[-3.432, 4.768]</td>
<td>0.749</td>
</tr>
<tr>
<td>Male to female</td>
<td>-0.668</td>
<td>[-4.768, 3.433]</td>
<td>0.749</td>
</tr>
<tr>
<td>Noticeability b</td>
<td>0.488</td>
<td>[-0.287, 1.263]</td>
<td>0.217</td>
</tr>
<tr>
<td>Identify as a person with a disability c</td>
<td>1.532</td>
<td>[1.095, 1.970]</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Education d</td>
<td>0.056</td>
<td>[-0.213, 0.326]</td>
<td>0.677</td>
</tr>
<tr>
<td>Race e</td>
<td>0.350</td>
<td>[-0.668, 1.369]</td>
<td>0.500</td>
</tr>
<tr>
<td>Income f</td>
<td>-0.241</td>
<td>[-0.436, -0.045]</td>
<td>0.016</td>
</tr>
<tr>
<td>Age (years) g</td>
<td>-0.089</td>
<td>[-0.122, -0.055]</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Number of disability-related conditions*noticeability</td>
<td>0.339</td>
<td>[0.099, 0.578]</td>
<td>0.006*</td>
</tr>
</tbody>
</table>
Results

![Graph showing the main effects of noticeability on stigma](image)

The graph illustrates how stigma increases with the number of disability-related conditions. The categories of responses include:
- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

The y-axis represents the stigma level, and the x-axis represents the number of disability-related conditions.
### Comparison of group means

<table>
<thead>
<tr>
<th>Number of disability related condition groups being compared</th>
<th>Noticeability Estimate</th>
<th>Confidence Interval</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 to 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>3.282</td>
<td>[0.893, 5.671]</td>
<td>0.007</td>
</tr>
<tr>
<td>2</td>
<td>4.638</td>
<td>[2.906, 6.370]</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>3</td>
<td>5.994</td>
<td>[4.535, 7.453]</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>4</td>
<td>7.351</td>
<td>[5.591, 9.110]</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>5</td>
<td>8.707</td>
<td>[6.278, 11.136]</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>4 to 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>0.820</td>
<td>[0.223, 1.418]</td>
<td>0.007</td>
</tr>
<tr>
<td>2</td>
<td>1.159</td>
<td>[0.727, 1.592]</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>3</td>
<td>1.499</td>
<td>[1.134, 1.863]</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>4</td>
<td>1.838</td>
<td>[1.398, 2.278]</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>5</td>
<td>2.177</td>
<td>[1.570, 2.784]</td>
<td>&lt;0.01</td>
</tr>
</tbody>
</table>
Discussion & Conclusion

• Provides us insight into the variables that play a role in stigma experiences for people with disabilities
• Provides us with insight into how disability related conditions can impact stigma experiences

• Future studies: investigate the role of stigma experiences in overall health of people with disabilities
Acknowledgements

• The Disabilities community
• Dr. Sheryl Thorburn
• Dr. Adam Branscum
• Dr. Kathleen Bogart
• Dr. Veronica Irvin
References


Thank you for your time
Have a lovely day!

Any questions?

Oregon State University

American Public Health Association
For science. For action. For health.
Involving Parents in Motor Assessment for Children with CP

Kimberley S Scott, PT, DPT
Board-Certified Clinical Specialist in Pediatric Physical Therapy
GRA, GTA, PhD Student
PEARL Laboratory
The Ohio State University
Cerebral Palsy (CP)

motor function

secondary impairments

postural control and gross motor function

participation
Secondary Impairments

• Contractures
• Spasticity
• Pain
• Fatigue
• Weakness
Limitations in mobility and activity in childhood are associated with:

- Decreased social participation
- Difficulty with self-care tasks
- Decreased quality of life
Parents: Engagement and Enactment
Approaches to Motor Assessment

**GMFCS**
- Gross Motor Function Classification Scale
- Levels I (mild impairment) through V (severe impairment) based on motor skills
- <5 minutes for service provider familiar with child to determine

**GMFM**
- Gross Motor Function Measure
- Gold standard motor assessment for children with CP
- 88 items across 5 domains
- 45-60 minutes for trained therapist to administer

**PEDI-Mob**
- Pediatric Evaluation of Disability Index Computer Adapted Test (PEDI-CAT) Mobility Subscale
- Parents complete relevant items based on item response theory
- 4 minutes
## Relationships among GMFCS, GMFM, and PEDI-CAT

<table>
<thead>
<tr>
<th>GMFCS Level</th>
<th>I (n=20)</th>
<th>II (n=6)</th>
<th>III (n=24)</th>
<th>IV (n=30)</th>
<th>V (n=17)</th>
<th>Total (n=97)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>4.89</td>
<td>3.11</td>
<td>2.47</td>
<td>3.23</td>
<td>3.57</td>
<td>3.41</td>
</tr>
<tr>
<td>(SD)</td>
<td>(1.84)</td>
<td>(1.36)</td>
<td>(2.15)</td>
<td>(2.09)</td>
<td>(2.55)</td>
<td>(2.27)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>9 (45%)</td>
<td>4 (67%)</td>
<td>9 (37%)</td>
<td>21 (70%)</td>
<td>11 (65%)</td>
<td>54 (56%)</td>
</tr>
<tr>
<td>Female</td>
<td>11 (55%)</td>
<td>2 (33%)</td>
<td>15 (63%)</td>
<td>9 (30%)</td>
<td>6 (35%)</td>
<td>43 (44%)</td>
</tr>
</tbody>
</table>
Relationship of PEDI-Mob and GMFM Scores
PEDI-Mob across GMFCS Levels
Conclusions

- Large, statistically significant correlation between PEDI-Mob and GMFM
- Differences in PEDI-Mob scores across GMFCS levels
- PEDI-Mob may estimate motor function when GMFM is not feasible
Implications and Plans for the Future

• Parents are likely accurate in objectively reporting the mobility and functional skills in their children with CP.
• Enactment of parent-implemented home programs is best when activities are contextualized based on parent goals for their child.
• Parent report on the PEDI-mob could be used as an adjunct to the GMFM to estimate gross motor function.
• With the support of a therapist, parents can use their knowledge of motor skills of their child to develop meaningful goals for intervention services.

Responsiveness of PEDI-Mob to change with therapeutic intervention across ages and GMFCS levels.
Questions?

References available upon request.
Universal Design for Measurement

Intentionally Including People with Disabilities in the Development and Testing of Health Measurement Instruments

Erin Vinoski Thomas, PhD, CHES
UNC Charlotte
**Background**

- People with disabilities comprise about a quarter of the population, but are underrepresented in health research\(^1\)

- Lack of measures of common health and psychological constructs validated in this population
  - Scale adaptation & modification

- Universal Design for Research\(^2\)

- Universal Design for Measurement (UDM)?
  - Proof-of-Concept: 3-step study
1. Scale Development

- Item development: Functional-Aesthetic Body Image Scale

- Data from qualitative study of body image and health among women with visible physical disabilities

- Extant literature

- 30 total items

- Participants’ phrasing retained
2. Expert Content Validation

• Subject matter experts (SMEs; $N = 6$) recruited using literature and professional networks

• Online survey
  • Relevance ratings
  • Qualitative comments

• 7 items that were not rated as relevant or highly relevant were revised based on qual. feedback
3. Consensus Testing

• Delphi Method
  • Iterative group communication process\textsuperscript{8,9}
  • Stakeholders rate content; content is collected by facilitator, then revised and retested until consensus is reached
  • Incorporate all relevant perspectives

• Current Delphi Study
  • Two rounds; online; women with \((n = 18)\) and without \((n = 15)\) disabilities
  • Women with disabilities represented a range of disability types
  • Analysis: T-tests; Hedges’ \(g\) as measure of effect size\textsuperscript{10}
Findings

• 23/30 items moved toward consensus between Rounds 1 and 2 of the process
  • Revision & retesting process works!

• 17/30 items had effect sizes < .20 after Round 2
  • Indicates very small or negligible difference in ratings between groups, or… consensus!

• In short: Process provides a method for choosing scale items that are rated similarly by people with and without disabilities to improve the Universal Design of the scale
UDM Framework

- Derive scale items from qualitative data generated from studies focusing on or including PWD
- Include PWD and collect disability demographic data in all scale development and validation studies
- Balance qualitative and quantitative feedback from SMEs and those with lived experience to refine scale
- Conduct rounds of consensus testing among people with and without disabilities as needed/feasible


