Identification of the expressions of self-awareness in children with PIMD

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Content of my presentation

• Theoretical framework (reminder)
• Method (reminder)
• Results
• Discussion
Theoretical framework

Primary SA
(0-18 months)
Zelazo, 2004; Munz, 2006; Rochat, 2012

Superior SA
Gallagher, 2011; Newen & Vogeley, 2003

SA development

Primary SA
perceptive
immediate experience

Superior SA
conceptual
meta-experience

Rochat’s multidimensional model of ecological self-awareness (ESA)

ESA manifests itself in the experience of one’s body as a differentiated, organized, active, situated and animated entity
Saulus’ psychodevelopmental model on self-awareness and PIMD
(Saulus, 2009, 2011, 2013)

Aim of my research:
Empirical validation of both theoretical models
Research questions

• How does ecological self-awareness (ESA) manifest itself in children with PIMD?

• Does the study of ESA indicators allow to differentiate subgroups inside the PIMD main group?

• What distinguishes these subgroups?

• How are distributed ESA indicators in each subgroup?

Method

Evaluation tools in PIMD research

Indirect evaluation tools

• Interviews
• Surveys
• Parents, DSPS, ...

Direct evaluation tools

• Physiological measurement
• Developmental psychology paradigm
• Situation-based list
• People with PIMD
Method

Creation of a situation-based list on ESA

Content

Inducing situations (N=35)

- «Standardized» tasks
- Data collected by the researcher

Natural observation situations (N=25)

- Daily-life in the classroom
- Data collected by the professionals

Scoring protocol

Three-level score

0= Expression of non critical behaviour

1= Doubt about the manifestation of the critical behaviour *

2= Expression of the critical behaviour

*(too fast? coincidence?) this score is described and specified in each item

Three measurements/item (T1, T2, T3)

Mean score/dimension
Psychometric qualities of the inducing-situations list

<table>
<thead>
<tr>
<th>Quality</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal consistency</td>
<td>Cronbach alpha = .897</td>
</tr>
<tr>
<td>Inter-coder agreement</td>
<td>81%</td>
</tr>
<tr>
<td>Intra-coder agreement</td>
<td>88%</td>
</tr>
<tr>
<td>Test-retest reliability</td>
<td>ICC = .850</td>
</tr>
<tr>
<td>Procedural reliability</td>
<td>95%</td>
</tr>
<tr>
<td>Convergent validity</td>
<td>p = .895, p &lt; .001</td>
</tr>
<tr>
<td>Social validity*</td>
<td></td>
</tr>
<tr>
<td>Tool validity</td>
<td>88%</td>
</tr>
<tr>
<td>Method validity</td>
<td>88%</td>
</tr>
<tr>
<td>Participation benefit</td>
<td>83%</td>
</tr>
</tbody>
</table>

Procedure

June 2014: Agreement of the Ethics Committee on human research in Lausanne

Pre-experimental stage N= 6
- Test and adaptation of the situation-based list
- Test and adaptation of the indicators (critical behaviors)

Experimental stage N= 20
- Administration of the situation-based-list
- Interobserver training
- Confrontation with 3 experts of PIMD based on videotapes
Sample

Common inclusion criteria for the two stages

- PIMD- spectrum (Nakken, 2007)
  - profound mental disabilities
  - profound neuromotor dysfunctions
  - frequent sensory impairments

Specific criteria:

<table>
<thead>
<tr>
<th></th>
<th>Pre-experimental stage</th>
<th>Experimental stage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>4-18 years old</td>
<td>4-12 years old</td>
</tr>
<tr>
<td>Selection</td>
<td>Profile selection*</td>
<td>No profile selection**</td>
</tr>
<tr>
<td>(Saulus’ model)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number</td>
<td>6</td>
<td>21</td>
</tr>
<tr>
<td>Exp. mortality</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>NTotal</td>
<td>5</td>
<td>18</td>
</tr>
</tbody>
</table>

* In order to maximize the heterogeneity: 2 profile I, 2 profile II, 2 profile III
** It is not a convenience sample

RESULTS
RQ1: How does ecological self-awareness (ESA) manifest itself in children with PIMD?
% of expression of ESA indicators

Ecological self

- Differentiated self: 6-50%
- Animated self: 40-80%
- Situated self: 25-90%
- Active self: 22-80%
- Organized self: 30-90%

RQ2: Does the study of ESA indicators allow to differentiate subgroups inside the PIMD main group?
Cluster Analysis

<table>
<thead>
<tr>
<th>Subgroups</th>
<th>Members</th>
</tr>
</thead>
<tbody>
<tr>
<td>« Cluster 1 »</td>
<td>N=1</td>
</tr>
<tr>
<td>Cluster 2</td>
<td>N = 7</td>
</tr>
<tr>
<td>Cluster 3</td>
<td>N = 10</td>
</tr>
</tbody>
</table>

Effect on cluster membership:
- X age
- X gender
- X facility
- ✓ Profile of PIMD

RQ3: What distinguishes these subgroups?
Central tendency

<table>
<thead>
<tr>
<th>Feature</th>
<th>Independent samples T Test</th>
<th>One sample T Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cluster 3 &gt; cluster 2</td>
<td>t(8)= -4.6, p&lt;.05</td>
<td>95% CI [1.2 à 1.56] (9)=17.36, p&lt;.05</td>
</tr>
<tr>
<td>Cluster 3 &gt; participant 1</td>
<td>t(8)= -4.6, p&lt;.05</td>
<td>95% CI [1.04 à 1.14] (8)=4.56, p=.004</td>
</tr>
<tr>
<td>Cluster 2 &gt; participant 1</td>
<td>t(9)=13.44, p&lt;.05</td>
<td>95% CI [1.02 à 1.32] (6)=37.48, p&lt;.05</td>
</tr>
</tbody>
</table>

Statistically significant differences between means:
Cluster 3 > cluster 2 (except « organized self »)
Cluster 3 > participant 1
Cluster 2 > participant 1 (except « active » + « animated » self)
Intensity index

- Global level

![Bar chart showing intensity index for participants and clusters]

Summary

What distinguishes subgroups is:

- Global level of performance
- Level of complexity of participant's behaviours
RQ3: How are distributed S-A scores in each subgroup?

Cluster 2: global level

Dispersion
Summary

Inside each cluster, S-A scores are distributed in a non-homogenous way

- Global scores level
- Dimension scores level
- Intensity index score
Discussion

- Validation of Rochat’ multidimensional model

![Diagram showing the multidimensional model of self]

Developmental logic: example in «active self» dimension

![Bar chart showing developmental logic examples]
Validation of Slaus' psychodevelopmental model

- Participant 1 // Profile I
  - no self-recognition
  - sensorial inputs not treated
  - no action towards objects

- Cluster 2 // Profile II
  - no self-recognition but interest in one's image
  - emergence of stimuli localization
  - manipulation/exploration of objects but no contingency awareness

- Cluster 3 // Profile III
  - emergence of self-recognition
  - organized and situated sensorial treatment
  - means-end skills in emergence
  - body self-exploration/pleasure

Limits

- Exploitation of the data gathered with a new tool, not yet validated

- Sample size/representativity

- Incompleteness of data
Strengths

- Building of the situation-based list
- Coding process
- Correspondence between my results and both theoretical models
- Subgroups identification inside the main group

Implications

- Development of direct observation tools
- Importance of the assessment of self-awareness skills in children with PIMD
- Importance of the distinction of different profiles of PIMD
Further researches?

- SA in a « life-span » perspective?

- assessment of the effects of an intervention on SA skills?

- assessment of interpersonal SA skills of children with PIMD, linked to the ESA skills?

- comparison between SA skills of children with PIMD and children with anencephaly?
Bibliography


