Physical health issues in persons with Severe or Profound Intellectual and Multiple Disabilities (SPIMD) 

a systematic review

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Research and Innovation Group in Health Care and Nursing
Numerous health problems
Negative impact on the quality of life

Limited or no verbal communication skills
Express discomfort through altered behavior
May not be recognized as a health problem

Restriction in tolerating regular diagnostic due to:
   - intellectual disability
   - physical/motor disabilities
   - sensory impairments

Hardly any standardized tools for assessment

Lack of adjusted measurements
Dependence of carers

2. Petry, Maes & Vlaskamp, 2009
3. Charlton, 2011; Carr & Owen-Deschryver 2007; Cooper et al., 2006; Davidson et al. 2003; Zijlstra & Vlaskamp 2005; Chadwick et al., 2008
5. Nakken & Vlaskamp, 2007; Pawlyn et al., 2009 p.103
Consequence

Risk of health problems being undiagnosed and untreated

5. Cooper et al, 2004; Kerr et al, 2003; Baxter et al, 2006; Davidson et al, 2003; Charlot et al, 2011; May & Kennedy, 2010
Numerous health problems can negatively impact the quality of life. Limited or no verbal communication skills may make it difficult to express discomfort through altered behavior. This can lead to the problem not being recognized as a health issue.

Restrictions in tolerating regular diagnostic processes can be due to intellectual disability, physical or motor disabilities, or sensory impairments. Hardly any standardized tools for assessment further complicates matters.

Knowledge about the prevalence and impact of health problems is limited.

PHD project
Based on these findings a screening instrument for health problems will be developed
Step 1

Aim

To systematically review the published data for the types and prevalences of physical health problems in adults with severe or profound intellectual and multiple disabilities.
Methods
Search strategy

Severe or profound intellectual and multiple disabilities

Severe or profound ID

AND severe or profound intellectual and multiple disabilities

Genetic syndrome

AND severe or profound intellectual and multiple disabilities

AND physical health related terms
Methods

Selection criteria for studies

• Published after 2004, in English
• Adults with severe or profound intellectual (and multiple) disabilities
• Physical health problems
• Separate analysis for people with severe and/or profound ID
Methods
Assessment of risk of bias

Cohort studies: SIGN-50 methodology checklist (SIGN, 2011)

Cross-sectional studies: risk of bias tool developed by Hoy et al. (2012)

External validity: representativeness with SPIMD

Internal validity: measurement and definition of physical health problem
Records after duplicates removed
\( n=5682 \)

Records screened
\( n=5682 \)

Full-text articles assessed for eligibility
\( n=83 \)

Severe and profound disabilities and genetic syndromes.
\( n=29 \)

Records excluded
\( n=5599 \)

Full-text articles excluded, with reasons
\( n=35 \)

- No separate data analysis done for severe/profound ID (\( n=21 \))
- No frequency rates (\( n=2 \))
- Definition degree of severe ID (\( n=1 \))
- No information about number profound and severe ID in research population (\( n=1 \))
- Patient exclusion/ inclusion criteria (\( N=2 \)):
  - (patients with health problems were excluded (\( N=1 \)), patients were only included if they were able to walk (\( n=1 \)))
- Meeting/ conference abstracts and posters (\( n=7 \))
- Full text not available (\( n=1 \))
Results 1
Description of the 23 studies

- Most cross-sectional
- Nine studies (S)PIMD
- Eight studies adults and children (0-82)
- 13 included adults (18-98)
Results 2

Quality assessment

External validity
1. Target population a close representation of the SPIMD group?
2. Sampling frame representative
3. Random selection used to select the sample
4. Likelihood of non-response

Internal validity
5. Data collection directly from the subjects
6. Definition health problem
7. Measurement health problem
8. Same mode of data collection for all subjects
9. Appropriate numerator(s) and denominator(s)?
Health problems identified in one study
Health problems identified in two studies
Health problems ≥ three studies meta-analysis

*Persons with SPID who used antipsychotic medication
Meta-analysis

Funnel Plot Epilepsy

Standard Error

Proportion
<table>
<thead>
<tr>
<th>Percentage</th>
<th>Condition and Diagnosis</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>63.9% (39/61)</td>
<td>PMLD and <strong>epilepsy</strong></td>
<td>Gittins, 2007*</td>
</tr>
<tr>
<td>71% (180/254)</td>
<td>PIMD and <strong>epilepsy</strong></td>
<td>Van der Heide, 2009*</td>
</tr>
<tr>
<td>79% (39/49)</td>
<td>PMD and <strong>epilepsy</strong></td>
<td>Petry, 2009*</td>
</tr>
<tr>
<td>66.3% (120/181)</td>
<td>PIMD and <strong>epilepsy</strong></td>
<td>Poppes, 2010*</td>
</tr>
</tbody>
</table>

- Target group similar
- All included children
- Questionnaire by proxy or medical records
• Prevalence rate 8% - 39.2%
• No definition or criteria were given for hearing problems
• Questionnaire by proxy or medical records
• Sensory problems are easily overlooked
Discussion

• Data about physical health problems are limited
• Overall studies were diverse and explored a variety of health issues
• Different terms were used for SPIMD
• No information concerning diagnostic assessment instrument and procedures
• Deduction of subjects in whom no accurate measurement could be obtained
Conclusion

- An overview of studies on physical health problems in people with SPIMD

- Implications: step 1 in the PHD-project: a screening instrument for health problems in people with SPIMD
Numerous health problems
Negative impact on the quality of life
Limited or no verbal communication skills
Express discomfort through altered behavior
May not be recognized as a health problem

Restriction in tolerating regular diagnostic due to:
- Intellectual disability
- Physical/motor disabilities
- Sensory impairments

Hardly any standardised tools for assessment

Knowledge about the health problems
Prevalence

Knowledge and impact of health problems
PHD project
Questions?

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References


