Stuart Nicholls & Kevin Southern

Considering Consent: Factors Influencing Parental Perceptions of Decision Quality When Accepting Newborn Screening
Disclosures

Nothing to declare
If we want to better understand parental decision making we need to consider the context in which screening is provided.
Background: Screening in the UK
Parental decision-making and newborn screening
Methods: Measures and modeling
Results
Conclusions
Screening in the UK

- 3-5 days post-birth, usually at home
- (Community) midwife led
- Informed consent:
  - “Explain the procedure to parents and record in the maternity record that newborn blood spot screening has been discussed and recommended, the booklet given and consent sought.”
- Verbal consent is adequate (written consent is required in Scotland).” [1]
Knowledge – recall issues
Education materials – use?
Uptake rates – administration? Low level of refusal
Decision quality
  - Decision-making process
  - Statistical variation
Aim

- To model identified factors that influence parental decisional quality within the context of newborn bloodspot screening
Methods

- Cross-sectional survey
- Survey items developed based on prior qualitative data and existing tools such as The General Trust in Physicians Scale [2,3] and Revised Susceptibility, Benefits, and Barriers Scale for Mammography Screening [4]
- Random sample (n=500) of parents from Merseyside and Cheshire
- Year 2008 (N=28348)
- Excluded if child subsequently died or severely ill
Methods

- Analyzed using:
  - Confirmatory Factor Analysis (measurement), and
  - Structural Equation Modeling (structural)

- Assessed using:
  - Satorra-Bentler $\chi^2$ (seek n.s. $\chi^2$)
  - Goodness of fit indices: RMSEA (<0.05), CFI (>0.9)
  - Parameter estimates (size, direction)
## Methods

<table>
<thead>
<tr>
<th>Latent variable</th>
<th>Indicator (scale)</th>
<th>Cronbach’s alpha</th>
<th>Factor loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived knowledge (PCK)</td>
<td>Perceived understanding of motivation (Mot)</td>
<td>0.854</td>
<td>0.916**</td>
</tr>
<tr>
<td></td>
<td>Perceived understanding of Procedural aspects (Proc)</td>
<td>0.816</td>
<td>0.805**</td>
</tr>
<tr>
<td></td>
<td>Perceived understanding of Condition (Cond)</td>
<td>0.898</td>
<td>0.744**</td>
</tr>
<tr>
<td>Attitudes toward screening (ATTSCR)</td>
<td>Perceived Risk (Risk)</td>
<td>0.775</td>
<td>0.443**</td>
</tr>
<tr>
<td></td>
<td>Perceived Benefits (Ben)</td>
<td>0.871</td>
<td>1.00**§</td>
</tr>
<tr>
<td>Perceived choice (CHOICE)</td>
<td>Ability to Make a Choice (Abch)</td>
<td>0.793</td>
<td>0.622*</td>
</tr>
<tr>
<td></td>
<td>Availability of Choice (Avch)</td>
<td>0.730</td>
<td>0.593**</td>
</tr>
<tr>
<td>Attitudes toward medicine (ATTMED)</td>
<td>Trust in the Midwife (Mid)</td>
<td>0.831</td>
<td>0.659**</td>
</tr>
<tr>
<td></td>
<td>Trust in the healthcare system (Trustsys)</td>
<td>0.629</td>
<td>0.782**</td>
</tr>
<tr>
<td>Decisional quality (DCQ)</td>
<td>Uncertainty Subscale of ODCS (Unc)</td>
<td>0.907</td>
<td>0.9**</td>
</tr>
<tr>
<td></td>
<td>Effectiveness Subscale of ODCS (Eff)</td>
<td>0.898</td>
<td>0.935**</td>
</tr>
</tbody>
</table>

**p<0.01, § = item constrained to have error variances greater than zero
Results

- 154 respondents (32%)
- 3 surveys had large amounts of missing data.
- Multiple imputation (ANOVA n.s.)

<table>
<thead>
<tr>
<th>Item</th>
<th>Number</th>
<th>%*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age group: &lt;30 years</td>
<td>50</td>
<td>32.5%</td>
</tr>
<tr>
<td>Number of children: 1</td>
<td>55</td>
<td>35.7%</td>
</tr>
<tr>
<td>Highest educational level: high school or below</td>
<td>31</td>
<td>20.1%</td>
</tr>
<tr>
<td>Ethnicity: White</td>
<td>147</td>
<td>95.5%</td>
</tr>
<tr>
<td>Household income: &lt; £11500</td>
<td>16</td>
<td>10.4%</td>
</tr>
</tbody>
</table>

* Indicates valid percent from respondents completing the question
Results

$\chi^2 (df=48) = 61.396, (p = 0.093)$

$CFI = 0.979$

$RMSEA = 0.043$

$R^2 (DCQ) = 66\%$

* = $p < 0.05$, ** = $p < 0.01$
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Conclusions

- Attitudes research tends to focus on the immediate test [5-7]. A failure to differentiate the general and specific may overemphasize the impact of specific attitudes to screening.
- Perceived choice positively affects decision quality.
- Role of the health care professional
The NBS system

Screening as a System of Care

Good Governance

Education

Enrolment

Test & Interpretation

Diagnosis

Retrieval

Intervention

Evaluation

Courtesy of Robin Hayeems, University of Toronto
Limitations

- Parents appeared to be older and more educated.
- The sample size is also relatively small, and did not allow for group comparisons, such as comparing primiparous and multiparous parents.
- The response rate of 32% is also relatively low, but comparable to other survey research in NBS [8, 9, 10].
- All parents had accepted newborn screening.
Acknowledgements

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