Congenital anomalies: parents' concerns and opinions towards public health policies and improved effectiveness of health services.

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BACKGROUND

The birth of a child with an unexpected diagnosis can increase family interactions with health services and professionals.

Evidence suggests that when parents are engaged partners with health care providers in decision making and report satisfaction with the health care services they receive, health care costs are reduced, and child health outcomes improve in this population.

Hence it is important to acknowledge what type of interactions and services parents perceived as sufficient or as lacking within the National Health Services.
**DESIGN**

**Aim:** describe parents perceptions of health services and public health policies in Portugal.

**Target population:** parents of children diagnosed with severe heart anomalies; *spina* bifida; orofacial clefts, Down syndrome and cerebral palsy.

**Data collection:** semi-structured online questionnaire.

**Procedures:** a web link to an online questionnaire was sent to focal points of 5 parents associations and professional institutions in Portugal in may 2018. Those associations then disseminated the web link to parents registered with each association.

**Data analysis:** thematic content analysis and descriptive analysis (frequencies).
RESULTS

Returned questionnaires: 254
Completed and returned questionnaires: 186 (73%)

Questionnaire returned by

<table>
<thead>
<tr>
<th>Organization</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Down Syndrom parents association (Pais21)</td>
<td>50</td>
</tr>
<tr>
<td>Cerebral Palsy intitutions</td>
<td>43</td>
</tr>
<tr>
<td>Others</td>
<td>39</td>
</tr>
<tr>
<td>Oral cleft association</td>
<td>30</td>
</tr>
<tr>
<td>Spina Bifida and Hydrocephalus Association</td>
<td>15</td>
</tr>
<tr>
<td>National Health Institute</td>
<td>5</td>
</tr>
<tr>
<td>Informal social network</td>
<td>4</td>
</tr>
</tbody>
</table>
RESULTS

Parents who responded

- **Women** (88.7%) and Men (11.3%)
- **Married/civil union** (79.6%)
- Up till **secondary education**
  (12 years of schooling) **(66%)**

<table>
<thead>
<tr>
<th>Age group</th>
<th>3%</th>
<th>12%</th>
<th>49%</th>
<th>28%</th>
<th>8%</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 to 24</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25 to 34</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>35 to 44</td>
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<tr>
<td>45 to 54</td>
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<td></td>
<td></td>
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<tr>
<td>55 to 64</td>
<td></td>
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</tbody>
</table>
87.3% of parents felt they had **got insufficient information** around the time of the diagnosis.  
98.3% of parents felt the needed to **look for further information** around the time of diagnosis.

- **33.6%** found the information to be sufficient.
- **66.6%** found the information to be comprehensible.
RESULTS

What do you feel would help you to play more effectively your role as a parent?

Open response thematic units

- Support (n=71)
- Time and availability (n=47)
- Financial resources (n=49)
- Inclusive society (n=24)
- Information (n=54)
- Health services (n=37)
What do you feel would help you to play more effectively your role as a parent?

**Support** (n=71)
- “social support”
- “further assistance by the state”
- “extra support to the families”

**Information** (n=54)
- “more... better... information”
- “reliable information from health professionals”
- “precise information about the pathology”
- “Information on rights of disable individuals”

**Financial resources** (n=49)
- “greater financial capacity”
- “financial resources, since I have quitted work”
- “financial help to buy technical assistance technology”
What do you feel would help you to play more effectively your role as a parent?

**Time and availability (n=47)**
- “time to accompany my son”
- “time and availability for the medical appointments and therapies”
- “flexibility in my work schedule”

**Health services (n=37)**
- “more accessible and more emphatic health services, with less bureaucracy and more available schedules”
- “physicians with increased know-how”

**Inclusive society (n=24)**
- “Inclusive society”
- “true integration”
RESULTS

Need statements about National Health Service (NHS)

*(Higher)* Disparity between parents perception of importance and reality within the NHS

- Professionals recognize and understand parent’s feelings
- Professionals coordinate and speak to one another
- Multidisciplinary intervention maintains after 18 years of age
- I receive written information about my child’s health status
- That professionals encourage parents to ask questions

![Bar Chart](chart.png)
RESULTS

Need statements about National Health Service

*Lower* Disparity between parents perception of importance and reality within the NHS

<table>
<thead>
<tr>
<th>Statement</th>
<th>Reality within the NHS</th>
<th>Very important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learn and be informed about how to care of my child by professionals</td>
<td>80%</td>
<td>100%</td>
</tr>
<tr>
<td>Be sure that when I am not present, my child get the best care</td>
<td>80%</td>
<td>100%</td>
</tr>
<tr>
<td>I make the final decision about the child’s treatment</td>
<td>80%</td>
<td>100%</td>
</tr>
<tr>
<td>To learn and be informed about how illness affects children’s growth and development</td>
<td>80%</td>
<td>100%</td>
</tr>
</tbody>
</table>
RESULTS

What were the main problems when dealing with the NHS?

Open response thematic units

- Lack of Information and knowledge (n=61)
- Access to healthcare services (n=54)
- Coordination between specialties (n=27)
- Specialized resources (n=38)
- Sensitiveness and lack of empathy (n=27)
- Access and communication to doctors (n=15)
RESULTS

What were the main problems when dealing with the NHS?

Lack of Information and knowledge (n=61)

“lack of information”
“lack of know how”
“Ignorance of the problem”
“Lack of information from clinical staff on correct referral”
“A considerable degree of ignorance of the condition”

“the long waiting period for exams and appointments”
“a lot of bureaucracy”
“the fact that the specialty is too far away”

“He was referred to the hospital for a development appointment. [...] A year later we were called to the first hospital visit”

Access to healthcare services (n=54)
What were the main problems when dealing with the NHS?

Specialized resources (n=38)

- “lack of skilled technicians”
- “shortage of specialized medical staff”
- “access to rehabilitation and specialties”

“Lack of coordination between services”
- “different procedures, the failure of transdisciplinary”
- “lack of coordination and collaboration among physicians of various specialties”

Coordination between specialties (n=27)
RESULTS

What were the main problems when dealing with the NHS?

Sensitiveness and lack of empathy (n=27)

“a lack of empathy towards our anxiety”
“I also find problematic the use of the term "poor baby“ and "poor little thing" by health professionals”

“Difficulties (sometimes total impossibility) of contact when dealing with professionals from the NHS”
“to be able to reach physicians in critic moments”

Access and communication to doctors (n=15)
FINAL POINTS

Information

- Parents perceived a lack of available information;
- Lack of adequate, reliable and precise information
- Information on the implications of treatment are however provided.

Health services can be displaced and unordered

- Parents perceived a lack of multidisciplinary interventions;
- Lack of coordination or communication between professionals and;
- There are difficulties accessing needed therapeutic interventions.

Parents felt overall confident on the health care provided and on the “training” they get from interacting with the professionals.
14th European Symposium on Congenital Anomalies

Thank you for the attention

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