Research priorities in the field of congenital heart disease as viewed by patients and physicians: A survey by the Competence Network for Congenital Heart Defects

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Introduction:
Patients and their relatives, as well as physicians of paediatric cardiology, cardiology and cardiac surgery were surveyed to identify current domains in the field of congenital heart disease (CHD) requiring further research and to thus consider the needs of those affected.

Methods:
Over a period of 30 days, an online survey concerning four groups of CHD (Fontan circulation, transposition of the great arteries [TGA] after atrial switch, TGA after arterial switch [TGA-ASO], tetralogy of Fallot [TOF]) was promoted. The online questionnaires comprised twelve issues each. For evaluation, a scale from 1 (no need for research) to 6 (urgent need for research) was used. Patients/relatives were asked questions specific to their diagnosis. Patients were recruited from the German National Register for Congenital Heart Defects.
596 patients/relatives took part (Fontan circulation: n = 189; TGA after atrial switch: n = 64; TGA-ASO: n = 90; TOF: n = 253), as well as 75 physicians (57.3% paediatric cardiologists, 28.0% cardiologists, 10.7% cardiothoracic surgeons and 4.0% other).
Additionally, the patients’ age, sex, educational background and employment status and the physicians’ sex, work areas and function were recorded. The total response rate of patients/relatives was 57.2%.

Results:
Apart from a few exceptions, patients rated all fields higher than physicians, thus assuming a greater need for research in all areas. With the exception of the group of TGA after atrial switch, far more females (68%) than males from the patients/relatives group took part in the survey. Female physicians assumed a greater need for research into psychosocial issues than their male counterparts.
Regarding the assessed need for research, at times significant differences were found between physicians of the different subspecialties. Patients and relatives in large part - albeit with different emphasis on and ranking of single topics - agreed with the physicians regarding the choice of CHD related topics primarily requiring further research.

Table 1: Overview of the topics rated highest

<table>
<thead>
<tr>
<th>Fontan circulation</th>
<th>„Failing Fontan“</th>
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<tbody>
<tr>
<td></td>
<td>Quality of life</td>
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<td>Career choices/pension</td>
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<td>Diagnostic imaging</td>
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<td>Anticoagulation</td>
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<tr>
<td>TGA after atrial switch</td>
<td>Catheter ablation, ICD implantation, sudden cardiac death</td>
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<td></td>
<td>Diagnostic imaging</td>
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<td>Diagnostics and treatment of heart failure</td>
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<td>Catheter based intervention, re-operation</td>
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<td>TGA after ASO</td>
<td>Dilatation of the great vessels, AV valve related complications, subsequent interventions/surgery</td>
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<td></td>
<td>Catheter ablation, ICD implantation, sudden cardiac death</td>
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<td>Problems related to the coronary arteries</td>
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<td>Diagnostic imaging</td>
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<td>Cognitive function</td>
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<td>TOF</td>
<td>Catheter ablation, ICD implantation, sudden cardiac death</td>
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Conclusions:
The topics considered to be the most important by both patients/relatives and physicians point to the everyday challenges of offering health care to named patient groups. Special emphasis should thus be placed on investigating these topics in the coming years.