

## Appendix 2

### Codes

<b>Theme</b>	<b>Subthemes</b>	<b>Codes</b>
Temporal aspects affecting the experience with decision-making	Lack of time while making the decision Difficulty to foresee the future	Lack of time Difficult to plan for the future
Losing control of the situation	Not having real choice Being forced into the decision Difficulty grasping the reality	Being forced into decision Difficulty to grasp reality Feeling not making the decision by themselves Being judged Conflict with doctors Information overload Not respecting parents Not having real choice
Transferring the power to decide to the doctors	Reluctance to make decision Transferring the responsibility to doctors Relying on the doctor's expertise Lack of confidence and medical expertise	Don't want to make the decision Lack of confidence No medical expertise Previous experience Transferring the responsibility to HCP Doctor's expertise

<p>To be a “good” parent and protect the child</p>	<p>Child in the centre-what is best for the child  Advocacy for the child  Trying everything possible</p>	<p>Taking responsibility for the decision  Advocacy  Including the child  Keeping hope  Keeping all options open  What is best for the child  Making the right decision  Trying all options of treatment  Outcome of the child  Quality of life  Keeping role of a parents  Abandoning the child  Protecting the child  Asking second opinion  Trying all options of treatment  Making difficult decisions</p>
<p>The emotional state of parents</p>	<p>Overall experience  Range of emotions  Guilt  Feelings after</p>	<p>Being exhausted  Difficult decision  Frustration  Guilt feeling  Regret about the decision  Emotions after  Having doubts  Overwhelming  Conflicts  Anger  Information overload</p>

<p>Sources of support to alleviate the parental experience</p>	<p>Behaviour of doctors Including parents in decision-making Having enough information Being supported by loved ones Faith</p>	<p>Faith and praying Having enough information Cooperation with parents Lack of support Respecting/not respecting parents Support from doctors Trust Specialist work as team Support from family Enough information Respecting parents' choices even if different Communication Telling truth</p>
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