Children’s information needs before coming to hospital for a planned procedure; informing the development of a child-centred app.

Lucy Bray, Ashley Sharpe and Victoria Appleton
Edge Hill University
Why do the project?

- Children often have unmet information needs when attending hospital and this can cause them anxiety and uncertainty.
- If children are prepared and informed about what will happen during a procedure they tend to have a better experience.
- There is a lack of child-directed information and children are often reliant on their parents to relay information to them.
- We do not know much about what children want to know about before they come to hospital for a procedure.
This study set out to investigate children’s perspectives of what information is important and valuable to know before attending hospital for a planned procedure.

This investigation was part of a larger study (funded by Innovate UK) to develop and evaluate a child-centred app (Xploro) to prepare children for hospital procedures.
What did the project do?

- Exploratory qualitative child-centred design.
- We used ‘write and tell’ sheets to underpin a semi-structured interview.
- We asked children what information they thought was important for children to know about before a planned procedure.
- If a child was struggling to think of any information, they were prompted to think about what information they had wanted to know about before coming to the hospital.
Who did we speak to?

- We spoke to 106 children (55 girls, 51 boys) aged 8-12 years old.
- We spoke to children in hospital having ultrasound scans, X-rays, blood tests, plaster casts, MRI scans with different experiences of visiting hospital.

<table>
<thead>
<tr>
<th>Treatment or procedure</th>
<th>Total (n=106)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Radiology</td>
<td>26</td>
</tr>
<tr>
<td>Medical</td>
<td>22</td>
</tr>
<tr>
<td>Surgical</td>
<td>24</td>
</tr>
<tr>
<td>Blood test</td>
<td>20</td>
</tr>
<tr>
<td>Plaster Removal</td>
<td>14</td>
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What did the children tell us?

• 616 pieces of information (‘questions’) were identified by the children as important to know about before attending hospital for a planned procedure.
• Many of the children commented that they had not known enough about what would happen when they came to hospital.
• The children in this study had mainly relied on their parents as the main information provider.
Children value a scaffolded approach to gaining information; asking questions to piece together and build up information about a planned procedure.
Procedural information; ‘what will happen?’

- All the children identified that it was important for children to have detailed information about a procedure.
  - What will happen?
  - Will it be dark?
  - What does the spray do?
  - Who is there?
  - Who will you see first?
  - Can a needle go right through your arm?
Sensory information; ‘Will I feel scared?’

- The children identified that it was important to know sensory information about a procedure (touch, taste, smell, hear) and the emotions a child might feel.
  - Will it hurt? *(invasive or non-invasive)*
  - Will I be scared?
  - How will it feel?
  - Will it be cold?
  - How does numb feel?
Self-regulation information; ‘What can I do to stay calm?’

- Useful to be provided with information about how to cope during a procedure (not all children - those with a longer hospital stay or those undergoing more invasive treatments).
  - Can mum hold my hand?
  - Should I just stay calm?
  - Do I have to see my insides on the screen?
  - Can I play on an I-pad?

Will my mum be with me?
Key points

- Children do not always get the information they want about having a procedure.
- Information about who will be there (actors), the environment (scene) and what will happen (the plot) helps children develop a realistic ‘sequential representation’ or script of a procedure.
- Children identified that information needed to be detailed, specific and was less helpful if it was broad or generic.
Key points

- Children identify the importance of three types of information about a planned procedure; procedural, sensory and self-regulation information.

- Children value a scaffolded approach to gaining and building up information and understanding about a planned procedure.

- Information provided to children before a procedure needs to be individually tailored to each child’s self-identified information needs – adults need to follow children’s lead.
Key Point

- It is important that any information resources being developed for children are developed with children.
Using the information to inform the development of a child-centred app.

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do we find out my ultrasound results straight away?</td>
<td>No answer</td>
<td>The original questions/answers sent across by DF/VA and A/A had three different questions and answers relating to this, but in the Xploro spreadsheet there is only 1 question and no answer</td>
</tr>
<tr>
<td>Does banana milkshakes hurt?</td>
<td>A banana milkshake doesn’t hurt. The banana milkshake is chalky and can taste a bit funny, though sometimes it’s flavoured.</td>
<td>Other answers try to ask for the milkshake to be flavoured so maybe put it here for consistency and so that the children know that they can ask.</td>
</tr>
<tr>
<td>Will I have to be held down for a CAT scan?</td>
<td>You won’t need to be held down when you have a CAT scan but if it’s on your head you might need something on your forehead to stop you moving. You will need to be very still when you’re having the scan but there’s nothing to worry about.</td>
<td>There is a chance that children may have to be held so this could be misleading. The original question/answer sent through by LVA/VA/A/A focused more on what the child can do to remain calm to prevent being held down, etc.</td>
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Thank you

brayl@edgehill.ac.uk
@lucybray9