Experience-based co-design to improve patient, family and staff experiences with cancer care

Mireille Brosseau

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• Children’s Hospital of Eastern Ontario (CHEO)
  – an academic pediatric health science centre providing care for children and youth aged 0 to 18
  – 2,500 staff, 6,200 admissions, 7,000 surgeries, 170,000 clinic visits and over 65,000 emergency room visits yearly
  – also runs specialized programs for eating disorders, autism, psychiatric mental health, sexual assault, telepsychiatry and early language development

• Senior leaders and family advisors looking for ways to systematically engage patients/families in the identification of quality issues and in the design and implementation of solutions

• Prioritization exercise led by Family Forum selected Experience Based Co-Design (EBCD) based on environmental scan of best practices (Fall 2014)

• Decision to start with oncology services where Lean process improvement processes and pt/family engagement already initiated
Aims

• Test the effectiveness of the EBCD approach as a way of integrating patient, family & staff perspectives in efforts to improve care

• Improve patient, family & staff experience

• Improve the oncology orientation process & support materials to ensure oncology patients, families & staff have the knowledge and resources to become good partners in care
Objectives

• Capture patient and staff experiences through observation, interviews and video (May – June 2014)
• Deepen understanding of the experience through 'feedback events’ (Fall 2014)
• Prioritize issues and recommend solutions for executive team approval and support (November 2014)
• Co-design, implement and measure the impact of smaller unit-based improvement initiatives (February, June – November 2015)
• Adjust and embed the EBCD approach and/or lessons learned into CHEO standards and practices (Ongoing)
G. Robert et al. “Patients and staff as codeesigners of healthcare services”, *BMJ* 2015;350:g7714
EBCD measures

• **Aim 1: Testing EBCD effectiveness**
  – Perceived collaboration/partnership
  – Patient/family/staff involvement
  – Increased understanding of experiences
  – Generation of improvement ideas

• **Aim 2: Improved “early days” experiences for oncology patients, families and staff**
  – Knowledge of roles/responsibilities and where/how to access resources
  – Consistency in messaging
  – Increased feelings of confidence
  – Knowledge and ownership of PFCC behaviours
To what extent do you feel there are meaningful and effective partnerships between oncology patients, families, staff and physicians?*

*Question asked at EBCD Feedback Events with staff (n=13) September 10th, 2014, and families (n=12) September 20th, 2014.
I felt safe and comfortable during this process, despite touchy/difficult subjects that were highlighted. (Staff)

Great summary of real issues. Hearing it from people (vs written documentation) makes a BIG difference. (Parent)

Great to hear both sides, especially that there is a great deal of commonality. (Parent)

Very excited about future projects that stem from the process. (Staff)
Outcomes

1. Redesign oncology patient/family orientation process and supporting materials
2. Optimize orientation for new staff
3. Develop “Know Me” tool
4. Revisit use of space and free space for private conversations with families
5. Raise awareness of oncology patient/family experiences in the Emergency Department to identify improvement opportunities

6 staff improvement ideas
8 patient and family improvement ideas
Pre-implementation measures

7. During the days following my oncology diagnosis, I felt empowered to be involved in my (or my child/youth's) care. / Pendant les jours qui ont suivi le diagnostic d'oncologie, je me suis senti(e) en mesure de participer aux soins que je recevais (ou que mon enfant ou adolescent recevait).

3. In the days following the patient's oncology diagnosis, I gave opportunities to patients and families to express their preferences in terms of how they want to be involved in their own (or their child/youth's) care.

### Patient/Family Experience Questionnaire Results:

% of Positive and Neutral /Negative Feelings

<table>
<thead>
<tr>
<th>Question</th>
<th>% Positive</th>
<th>% Neutral + % Negative</th>
<th>Number of Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>How did you feel about the way you received the cancer diagnosis?</td>
<td>62%</td>
<td>38%</td>
<td>13</td>
</tr>
<tr>
<td>How did you feel when you met with various members of the oncology team?</td>
<td>50%</td>
<td>50%</td>
<td>16</td>
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<tr>
<td>How do you feel about the information you were given following the cancer diagnosis?</td>
<td>14%</td>
<td>86%</td>
<td>14</td>
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<tr>
<td>How did you feel when you/your child received their first chemo treatment?</td>
<td>11%</td>
<td>89%</td>
<td>18</td>
</tr>
<tr>
<td>How do you feel about going home for the first time after diagnosis?</td>
<td>56%</td>
<td>44%</td>
<td>16</td>
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Lessons learned

• Importance of integrating patient and family engagement and quality improvement efforts earlier in process
• Need to tighten timelines and clarify reporting structure
• Better connection/link between patient experience and quality improvement teams
• Current success attributed to EBCD key participants’ ownership and will to implement improvements
# EBCD and Lean integration @ CHEO

<table>
<thead>
<tr>
<th>EBCD</th>
<th>Lean</th>
<th>How we bridged the gap?</th>
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<tbody>
<tr>
<td><strong>Origins</strong></td>
<td>UK researchers (2006) in healthcare services</td>
<td>Japanese engineer (1930s) in manufacturing industries</td>
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<td><strong>Mindset</strong></td>
<td>Abundance of curiosity</td>
<td>Problem-solving</td>
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<td><strong>Focus</strong></td>
<td>Patient, family and staff experiences (how did it feel?)</td>
<td>Value-added activity (what did you do – would your customer pay for it?)</td>
</tr>
<tr>
<td><strong>Process</strong></td>
<td>Pt/families, staff working together as “quality detectives” to bring about change</td>
<td>Plan, Do, Check and Act (PDCA) cycles to identify and eliminate waste</td>
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</tbody>
</table>
Questions

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