Implementing Experience-Based Co-Design: Lessons from the Trenches

The Beryl Institute
Patient Experience Conference
April 14, 2016
Who We Are

• **Joy Hanson:** Administrative Director, Care Coordination

• **Jennifer Phillips:** Innovation Director, Kaizen Promotion Office
Session Objectives

• **Objective 1:** Understand basic ethnography methods useful in a healthcare setting

• **Objective 2:** Learn factors influencing data collection experiences for all involved

• **Objective 3:** Identify strategies to increase success in using data and patient-family involvement to fuel improvements
Create full partnership with patients and families to improve and transform our delivery of care.

Do we really know what matters?

Understanding customer experiences stimulates creative thinking and breakthrough innovation.

Customers define value-added.
Experience-Based Design: Our Approach to Ethnography
emotion

1. an affective state of consciousness in which joy, sorrow, fear, hate, or the like, is experienced, as distinguished from cognitive and volitional states of consciousness.

2. any of the feelings of joy, sorrow, fear, hate, love, etc.

3. any strong agitation of the feelings actuated by experiencing love, hate, fear, etc., and usually accompanied by certain physiological changes, as increased heartbeat or respiration, and often overt manifestation, as crying or shaking.

4. an instance of this.

5. something that causes such a reaction: the powerful emotion of a great symphony.
The Value of Emotion Words

EMOTION WORD LIST
December 2012 Version

<table>
<thead>
<tr>
<th></th>
<th>Afraid</th>
<th>Enthusiastic</th>
<th>Ignored</th>
<th>Resentful</th>
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<tbody>
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<td>Angry</td>
<td>Frustrated</td>
<td>Insecure</td>
<td>Sad</td>
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<td>Compassion</td>
<td>Grateful</td>
<td>Jealous</td>
<td>Safe</td>
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<td>Confident</td>
<td>Great</td>
<td>Joyful</td>
<td>Satisfied</td>
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<td>Depressed</td>
<td>Guilty</td>
<td>Loyal</td>
<td>Secure</td>
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<td>Disgusted</td>
<td>Happy</td>
<td>Okay</td>
<td>Sense of Accomplishment</td>
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<td>Disrespected</td>
<td>Hatred</td>
<td>Optimistic</td>
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<td>Empowered</td>
<td>Hopeful</td>
<td>Peaceful</td>
<td>Valued</td>
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<td>Enjoyment</td>
<td>Hopeless</td>
<td>Pleased</td>
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A philosophy and set of methods focused on an understanding of the experiences and emotions of those who are involved in receiving and delivering healthcare services, striving to understand what people naturally do and feel.

What really matters to our customers?
Experience-Based Design Methods

- Observations
  - Fly on the wall; subtle presence
  - Big ears, big eyes, small mouth

- Interviews
  - Collect stories, guide through an experience
  - Open-ended questions

- Experience Questionnaires
  - Visual depiction of process
  - Customers select emotions at each touch point

- Focus Groups
  - Small group
  - Guide through a common experience
  - Open-ended questions

- Video Ethnography
  - Observation + interview elements
  - Can be used to shadow or get outside our walls

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A touch point is a “moment of engagement when feelings and emotions are increased, positively or negatively.” We think of them as memory-making moments.

Observation, storytelling & emotion words help you identify touch points.
EBD Helps Lean & Innovation

- Waste = any task or item not adding value from perspective of customer
- Negative emotions create waste
- EBD part of VMPS (lean) data set
  - Patient Experience Flow mapping
  - Flows of Medicine
  - EBD observations prior to stopwatch
  - Clouds on value stream maps
  - Metrics
Lessons from the Trenches
Story of the Alcohol Withdrawal Project
Tricky Topic to Study Experiences

Started by just observing and listening on units, open to whatever we would learn.
Discovered Lots of Negative Staff Emotions

From doctors:

“Sad.”

“I am not sure they are really linked in resources to get help.”

“Worried about their follow up and return to drinking.”

“Scared for the patient.”

From nurses:

“It’s hard to have faith when we get the same ETOH patient over & over & know their patterns.”

“I believe that allowing patients to withdrawal from ETOH who have no intention of quitting ETOH is an unnecessary risk to patient safety and causes discomfort that could be easily eliminated by prescribing ETOH.”

“I feel they are just going back to drinking.”

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Thank you for TRANSFORMING HEALTHCARE with us. By completing this questionnaire—YOU are helping us improve everyone's experience at Virginia Mason.

### Can You Tell Us About Your Typical Experience with: Managing patients with alcohol withdrawal?

<table>
<thead>
<tr>
<th>How do you feel when you perform the CRIWA?</th>
<th>Circle ONE WORD that best describes your feeling</th>
<th>Frustrated</th>
<th>Safe</th>
<th>Okay</th>
<th>Depressed</th>
<th>Sense of Accomplishment</th>
<th>Guilty</th>
<th>Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>How do you feel when you are administering medications in response to CRIWA scores?</td>
<td>Circle ONE WORD that best describes your feeling</td>
<td>Satisfied</td>
<td>Sense of Accomplishment</td>
<td>Afraid</td>
<td>Okay</td>
<td>Valued</td>
<td>Guilty</td>
<td>Insecure</td>
</tr>
<tr>
<td>What do you feel about the safety of pts. experiencing alcohol withdrawal?</td>
<td>Circle ONE WORD that best describes your feeling</td>
<td>Okay</td>
<td>Guilty</td>
<td>Depressed</td>
<td>Optimistic</td>
<td>Resentful</td>
<td>Hopeful</td>
<td>Empowered</td>
</tr>
<tr>
<td>How do you feel when pts leave the hospital after acute withdrawal?</td>
<td>Circle ONE WORD that best describes your feeling</td>
<td>Pleased</td>
<td>Guilty</td>
<td>Successful</td>
<td>Sad</td>
<td>Safe</td>
<td>Okay</td>
<td>Hopeless</td>
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**Comments:**
- At first, patients are happy to have a nurse who cares about them.
- They are usually happy to leave.
- Sometimes patients are telling me what I think they are saying, but they are actually doing it.
- It is really helpful to have a nurse who cares about patients.

---

**Big issue is patients who want to leave AMA. They are happy because they have a nurse who cares about them.**
Discovered Important Touch Points

Managing patients with alcohol withdrawal?

Customer Experience Questionnaire Results:
% of Positive and Neutral /Negative Feelings

<table>
<thead>
<tr>
<th></th>
<th>% Positive</th>
<th>% Neutral</th>
<th>% Negative</th>
<th>Number of Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>How do you feel when you</td>
<td>22%</td>
<td>78%</td>
<td>7%</td>
<td>9</td>
</tr>
<tr>
<td>perform the CWA?</td>
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<tr>
<td>How do you feel when you</td>
<td>22%</td>
<td>78%</td>
<td>7%</td>
<td>9</td>
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<td>are administering medications in response to CWA scores?</td>
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<tr>
<td>What do you feel about the</td>
<td>27%</td>
<td>73%</td>
<td>7%</td>
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<td>safety of pts. experiencing alcohol withdrawal?</td>
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<tr>
<td>How do you feel when pts</td>
<td>7%</td>
<td>93%</td>
<td>9%</td>
<td>15</td>
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<td>leave the hospital after</td>
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<tr>
<td>acute withdrawal?</td>
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</tbody>
</table>

RN and MD Experience
But How to Get the Patient’s Voice?

Traditional EBD interviews didn’t feel practical or appropriate
Constraints Fostered Creativity

Alcoholics Anonymous®

CHARLES B. TOWNS HOSPITAL
293 Central Park West
New York, New York
For ALCOHOLISM and DRUG ADDICTION

This institution has specialized in addictions for over 30 years. Its method of treatment has been fully described in THE JOURNAL A. M. A.; in The Handbook of Therapy, from the A. M. A. Press; and in other scientific literature. The treatment is a regular hospital procedure, and provides a definite means for eliminating the toxic products of alcohol and drugs from the tissues. A complete Department of Physical Therapy, with gymnasium and other facilities for physical rebuilding, is maintained. Operated as an “open” institution. Physicians are not only invited but urged to accompany and stay with their patients.

This advertisement for the facility where A.A. cofounder Bill W. received treatment ran in the same issue of the Journal of the American Medical Association as a review panning the newly published Big Book.
New Community Partnerships

Peer Support Visit Flow

1. PT admitted & ETOH issues identified
2. PT agrees to peer support visit
3. SW consult “Support visit arranged”
4. Patient signs - “Authorization to Release Patient Health Information” form
5. Email (Unit general email address) Request to peer support contact
6. VM Staff Documents & Handoffs in Rounds
7. Peer support contact sends confirmation
8. Same day as referral Peer support volunteer arrives & check-in @ RN Station

To: vm12stop@seattlepi.org

SUBJECT: VM peer support Request

Message: Pt Name, sex, location (building, floor, room #, phone extension for unit)

Scripting for initiation of conversation offering Peer Support visit:

AFTER Confirming Stage of Change Contemplation or Preparation/Action

1. Discuss alcohol/health risk:
   Patient specific: alcohol withdrawal AND OTHER ALCOHOL related medical problems (e.g. pancreatitis, alcohol related liver problems, GI bleed)
   SCRIPT: “You are experiencing alcohol withdrawal because you suddenly quit drinking. Your GI bleed (or other specific conditions of concern to the patient) is related to your drinking.”
   “Tell me the steps you have been thinking about to make a change in your drinking.”

2. “Your care plan includes a meeting with a social worker. The social worker can explore treatment options with you.”

3. Offer peer support visit:
   “To support you I can request a visit by a person who is recovering from an alcohol use disorder. They will be able to provide support and talk with you about their experiences and recovery. This visit will happen before discharge, usually within a day.”
   “Currently the person is a volunteer from Alcoholics Anonymous.”
   “Tell me how you would feel about a visit from a person someone from AA (or other)?”

RN Staff Documents

Visit Occurred; “Peer support visit complete”

Wants VM Help with referral to Tx

NO

YES

Peer support volunteer visits Pt

Peer support visitor inform VM Staff regarding desire for Tx; SW consult updating MSW on desire for further treatment resources
### Staff Roles in the Pathway of the ETOH Patient

<table>
<thead>
<tr>
<th>Standing Orders</th>
<th>&quot;Golden Window&quot;</th>
<th>Active Withdrawal</th>
<th>Completed Withdrawal</th>
<th>Safe to Discharge</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MD:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Detailed EtOH history</td>
<td>Maintaining order set</td>
<td>Renew CIWA/MINDS q24hr</td>
<td>Discontinue CIWA/MINDS</td>
<td>Safe medication levels</td>
</tr>
<tr>
<td>Date of last drink</td>
<td>Maintaining open communication with RN/PCT/MSN</td>
<td>Match medication dosing to present symptoms</td>
<td>Assess medication usage</td>
<td>Prescriptions written/sent</td>
</tr>
<tr>
<td>Pattern/volume of use</td>
<td>Include RN/PCT in MD rounds</td>
<td>Include RN/PCT in MD rounds</td>
<td>Include RN/PCT in MD rounds</td>
<td></td>
</tr>
<tr>
<td>Hx withdrawal/seizures</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Activate EtOH order set</td>
<td></td>
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<tr>
<td><strong>RN:</strong></td>
<td></td>
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<tr>
<td>Assessment</td>
<td>Assess patient’s openness to peers</td>
<td>Communicate high risk behaviors to MD</td>
<td>Communicate high risk behavior to MD if still an issue</td>
<td>Discharge teaching</td>
</tr>
<tr>
<td>Review orders</td>
<td></td>
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<td></td>
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<tr>
<td>Admin PRN/scheduled meds</td>
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<tr>
<td>Consult CNL if there is history of a care agreement</td>
<td></td>
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</tr>
<tr>
<td>EtOH History:</td>
<td>Introduction of Care Agreement and have patient sign</td>
<td>CIWA/MINDS scoring</td>
<td>Taper/Transition to PO medications if tolerated</td>
<td>Communicate to PCT that patient is ready to discharge</td>
</tr>
<tr>
<td>Last drink</td>
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<tr>
<td>Volume</td>
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<tr>
<td>Withdrawal Hx:</td>
<td></td>
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<tr>
<td>Yes</td>
<td>No</td>
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<tr>
<td>Seizure Hx:</td>
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<tr>
<td>Yes</td>
<td>No</td>
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<tr>
<td><strong>MSW:</strong></td>
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<tr>
<td>Automatic consult ordered when MD initiates EtOH order set</td>
<td>Has seen the patient and entered notes on their consult</td>
<td>Maintain communication with the care team</td>
<td>Start discharge planning</td>
<td>Transitional resources provided (PRN)</td>
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<tr>
<td></td>
<td>intro resource to the patient</td>
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<tr>
<td><strong>PCT:</strong></td>
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<tr>
<td>Admission documentation</td>
<td>Encourage ambulation/ADLs</td>
<td>Report high risk symptoms/behaviors to RN</td>
<td>Encourage self-care</td>
<td>Get patient discharge ready:</td>
</tr>
<tr>
<td>Safety Sweep:</td>
<td></td>
<td></td>
<td></td>
<td>- Remove IV(s)</td>
</tr>
<tr>
<td>Contraband sent to safe</td>
<td>Encourage patient’s self-care</td>
<td>Promote safety</td>
<td>Encourage ambulation</td>
<td>- Gather belongings</td>
</tr>
<tr>
<td>Fall precautions/bed alarm</td>
<td>Report any high risk symptoms/behaviors to RN</td>
<td>Encourage nutritional intake if safe</td>
<td>- Call for transport</td>
<td></td>
</tr>
<tr>
<td>Mats/seizure pads</td>
<td>Maintain safety sweeps for contraband</td>
<td>Maintain safety sweeps for contraband</td>
<td>Maintain safety sweeps for contraband</td>
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<tr>
<td>Walker ordered/gait belt</td>
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<td>Purell removed-sign placed</td>
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### Daily Maintenance
- Maintain MD/RN/PCT communication—RN must be included in MD rounds
- Daily/PRN assessment of decisional capacity in event of AMA
- Maintain safe medication levels

### Open Communication on AMA Risk Factors
- Maintain safety of patient and staff
- Daily sweeps for contraband
Story of the Delirium Study
A did not have any helium at your hospital.
Comments: I was too scared to mention it. I didn't know who was real and who I imagined. I was sure they were trying to kill me.

The delirium that I experienced (if that is what it was?) were night episodes that were the worse ever experienced. It was as if I were awake in another world and the continued as I experienced the memory of them the next morning. It was sometime (30 min or so) to realize the reality of the new hospital day & routine.

This was overwhelming experience that took a long, long time to put in some kind of perspective.
Initial Delirium Study Plan

Week 1
Create data plan
Contact Analytics with request for patient list (if indicated)

Weeks 2-3
Conduct ebd observations
Create and send patient/family recruitment mailing
Schedule ebd staff interviews

Weeks 4-8
Continue scheduling patient/family interviews
Conduct ebd interviews
Analyze ebd interviews, identifying touchpoints

Weeks 9-12
Create and PDSA questionnaires
Distribute questionnaires and tally data

Weeks 13-14
Write ebd summary of findings for use in kaizen work
Observation Template

OBSERVATION
- What are you wearing?
- Are you comfortable?
- What is your position?
- What is your mood?
- Are you smoking?
- Are you drinking alcohol?
- Are you taking any medications?
- Are you allergic to any substances?
- Are you pregnant?
- Are you breastfeeding?
- Are you menstruating?
- Are you taking any dietary supplements?
- Are you taking any vitamins?
- Are you taking any home remedies?
- Are you taking any natural remedies?
- Are you taking any over-the-counter medications?
- Are you taking any prescription medications?
- Are you taking any illegal substances?
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“I thought my caregivers were attackers, and when I kept being reminded that I was in the hospital I thought certain employees were hostage victims and I was trying to save them, I was trying to save myself, but during it all I was pulling tubes out, I was pulling IVs out, I was real combative to the point where I was put in soft restraints, but I do remember that no one told me ... it was still kind of like minimized as far as the delirium ...”

“Most families recognize that their family members aren't themselves and they get "worried" or "afraid" that this will not resolve itself. Most feel afraid for the most part as stated earlier that this is because they don't know if this is temporary or long-term situation for the family member. As nurses we expect it, but sometimes families are not aware.”
The delirium was worse the 1st time and markedly got worse and worse over the week we were home. I called his Dr's office on July 30, and they told me to call 911. So for the time that he was getting worse and worse, I thought he'd get better and I was shocked and frightened when he continued over the week to actually get worse and worse.

Many of my responses are in the more negative form. Partly because I did not feel that I had been informed as to what the delirium experience was, and how it would affect the patient. For example, when Dave was ripping the tubes out and getting out of bed, I assumed that it was discomfort he felt, even though not conscious. It would have been good during those times, to have delirium symptoms explained. Then let me know that these types of behaviors will happen when a person is in CCU. Then... here are some ways you can help us to monitor... you know him best... so look for ways there are behavior changes.
When it was time to bring him home they got a nurse to come in to therapy & bath him, but it was his 3rd care area & he was very unaware & I was new there. Still does not remember any of it. And I really do not think he will ever return clear back to what he was before. He is doing well, but there is still something only a wife who lives with him can notice or see.

shaking, extreme anxiety, I could have used a lot more support from staff that time. He had “code shang” called twice and ended up in the ICU for 5 days, with 4-way restraints, intubation, and the whole bit (not to mention). I needed more information about what severe withdrawal could look like and how to deal with it as a caregiver.
From EBD Summary Report:

Involved families are good at pushing their family members to stay awake. Sometimes family members will stay through the night so that a familiar face will keep the patient at ease. Some members will bring in friends for visits so that familiar faces and activities can be achieved during the visit.

The more confident and comfortable family members are with healthcare the better. If a family member is not comfortable or knowledgeable about healthcare or a healthcare setting, then family tends to sit back and wait for the team to do all the work with little information.
Alert card created by patients and family members for trialing during hospital stays

**ALERT!**

Disoriented
Extreme Emotions
Lethargic
Inattention
Restless
Impulsive
Unpredictable
Memory Change

**Delirium requires immediate evaluation**

**ACTIONS**

1. Call for Help
2. Stay with Patient
3. Keep Calm

**Delirium requires immediate evaluation**
<table>
<thead>
<tr>
<th>After-Action Review on (list project or situation)</th>
</tr>
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<tbody>
<tr>
<td>(Date)</td>
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</tbody>
</table>

1. **What did we set out to do?** Key intent? What we wanted to happen?

2. **What did we actually do?** Key facts about how it unfolded? What a video camera would show?

3. **What have we learned?** What we know now that we didn’t know before? Strengths and weaknesses discovered? Advice we would give to someone facing this situation?

4. **What are we going to do?** How to sustain strengths and improve weaknesses? Individual or group actions we'll take?

5. **Who are we going to tell?** Other teams or colleagues who will benefit from this knowledge? Best way to share?
General Insights

- Do not skip doing observations (without a stop watch!)
- Don’t give up or not even start just because you assume you can’t
- Apply sensitivity, ethics and creativity to how you study experiences
- Expect and embrace being out of your comfort zone
Benefits We’re Seeing

- Expanding our depth of understanding
  - Busting assumptions
  - Uncovering issues
  - Sometimes validating perceptions & hunches
  - Taking us in surprising directions
- Creating change receptivity
- Helping prioritize improvements
- Transforming the culture
Pitfalls We’ve Learned So Far

• Can underestimate the intensity of the experience
• Teams not always ready to follow through with results
• Limitations of qualitative data for measuring change
• Can rely too much on convenience sampling
Ways to Mitigate Challenges

• Assess for potential emotional intensity during planning stage
  • Be intentional about involving subject matter experts
  • Plan team support strategies
• Get creative about data collection
• Do IRB review
  • Assess for quality improvement vs. human subjects research
• Involve ops teams throughout
Action Planning

• Reference your worksheet
• Gather at the wall stations
• Discuss anticipated pitfalls & solutions for your projects
WE ALL HAVE A STORY TO TELL
Virginia Mason

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