The Patient Innovator in Resilience

Make It So: enacting resilience in everyday work

Resilience Health Care Net meeting

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CANADA

Carolyn Canfield
citizen-patient
honorary lecturer
Department of Family Practice
Faculty of Medicine
WELCOME TO THE UNIVERSITY OF BRITISH COLUMBIA
safety is the absence of harm
Patient Safety: a Definition

“Management of RISK over time in order to MAXIMIZE benefit and MINIMIZE harm to patients in the healthcare system”

managing risk

SAFETY

QUALITY
managing risk

SAFETY  ... it takes collaboration!  QUALITY
‘Managing Risk’ with Resilience engineering

Resilience is the intrinsic ability of an organisation to adjust its functioning prior to, during, or following changes and disturbances, so that it can sustain required operations under both expected and unexpected conditions.
‘Managing Risk’ with Resilience engineering

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...to achieve its goals...
‘Managing Risk’ with Resilience engineering

Resilience is the intrinsic ability of an organisation to adjust its functioning prior to, during, or following changes and disturbances, so that it can sustain required operations under both expected and unexpected conditions. To achieve its goals:

- Goals over a unit of work (patient and clinician)
- Goals over a course of treatment (patient and therapeutic team)
- Goals over a lifetime of well-being (patient and health service)
In order to be resilient, the organisation must have four basic abilities.

- **Respond** to regular and irregular conditions in an effective, flexible manner,
- **Anticipate** long-term threats and opportunities,
- **Learn** from past events, understand correctly what happened and why,
- **Monitor** short-term developments and threats; revise risk models.
Person-centred Care?
what care looks like from a system perspective
what wellbeing looks like from a patient perspective
Ecosystems are not only more complex than we think, they are more complex than we CAN think.

Egler, Frank E, *The Nature of Vegetation* 1977
- skills
- respect
- awareness
- competence
- trust
- calmness
- accountability
- intuition
- communications
- interdependence
- and more!
Adapted from http://resilienthealthcare.net/onewebmedia/Johnson_Lane.pdf
Healthcare as a Complex Adaptive System

Patient-hood as a Complex Adaptive System
Wellbeing of the patient

Care from the system
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JLA Needs you
We particularly want to hear from people with the following skills and/or experiences.

- Allied health professionals who work in emergency departments
- Clinicians of all levels
- Data analysts
- Devolved nation representatives
- Experience of patient involvement in research
- Nurses who work in emergency departments
- Patients and lay representatives
- Systematic reviewers

What if I don't work in an emergency department, or don't live in the UK?

It does not matter. If you have a great idea or question let us know. If a question is important and relevant we will use it in the priority setting exercise.
Top Ten research priorities for Emergency Medicine

1. What is the best way to reduce the harms of emergency department crowding and exit block? We need a better measure of crowding that drives sensible improvements for the seriously ill and injured, adolescents and the frail elderly.

2. Is a traditional ED the best place to care for frail elderly patients? Would a dedicated service for these patients be better (involving either a geriatric ED, or geriatric liaison services within the ED), or given that this population is expanding should our current services be tailored towards this group?

3. How do we optimise care for mental health patients; including appropriate space to see patients, staff training, early recognition of symptoms, prioritisation compared to physical illness, and patient experience?

4. With regards to how ED staff development is managed, what initiatives can improve staff engagement, resilience, retention, satisfaction, individuality and responsibility?

5. How can we achieve excellence in delivering end of life care in the ED: from the recognition that a patient is dying, through symptomatic palliative treatment, potentially using a dedicated member of staff to work with palliative patients and their relatives, and handling associated bereavement issues?
Top Ten priorities for Emergency Medicine

6. The effects of implementing new techniques in assessing patients with chest pain (which include new ways of using high sensitivity troponin tests, and decision rules such as the MACS rule and the HEART score) in practice. Would patients like a say in what is an acceptable risk, and should these tools be used alongside shared decision making to provide safe and appropriate care, minimise unnecessary risk and inconvenience for patients?

7. What is the ideal staffing for current UK EM practice, including doctors, nurses, healthcare assistants, porters, radiographers, clerical and reception staff?

8. Do early undifferentiated (broad spectrum) antibiotics in suspected severe sepsis have a greater benefit and cause less harm to patients than delayed focussed antibiotics in the ED?

9. In adults who are fully alert (GCS 15) following trauma does cervical spine immobilisation (when compared to no cervical spine immobilisation) reduce the incidence of neurological deficit, and what is the incidence of complications?

10. Which trauma patients should be transferred to a Major Trauma Centre rather than going to another hospital first?

80 more priority setting partnerships at http://www.jla.nihr.ac.uk/priority-setting-partnerships/
PaCER is a group of patient researchers, trained in qualitative health research, who are creating a new collective research voice with, by, and for patients. PaCERs are citizens with a variety of health conditions who are trained to use their engagement skills to conduct health research.
The Experience of Living with Chronic Joint Pain

Patients Matter: Engaging Patients as Collaborators to Improve Osteoarthritis Care in Alberta

Figure 1. Experience

Experience of Pain

Mental Aspects of Pain

Depression
No Help
Despair
No Future

Unpredictability

Physical Pain

Hurt
Look Normal, Feel Pain
Intractable
Worn Out
Recovery from Activity
Loss of Sleep

https://pacerinnovates.ca/
Figure 2. Hiding Pain.

- Being hidden by pain: OA patients are "invisible"
  - Experience and Perceptions
    - Burden
    - Elderly
    - Weakness
    - Complainer
    - Fear
  - Hiding Pain
  - Actions
    - Withdraw
    - Saving Face
    - Avoid
    - Minimize
  - The individual effort to hide

https://pacerinnovates.ca/
Figure 3. Standing up to Pain.

- Adaptations
  - Pacing
  - Nurturing Self
    - Professional Help
    - Diet
    - Supplements
    - Exercise

- Mental Strategies
  - "Positive Stuff," Aphorisms
  - Mind Over Matter
    - Sticking up for Yourself
  - Humour

Action
Patients are doing it for themselves: A survey on disease-specific knowledge acquisition among people with Parkinson's disease in Sweden.

Riggare S¹, Höglund PJ², Hvitfeldt Forsberg H, Eftimovska E, Svenningsson P, Hägglund M¹.

To manage her Parkinson's disease, Sara Riggare spends 1 hour in neurological healthcare and 8,765 hours in selfcare per year.
Patients as partners in Enhanced Recovery After Surgery: A qualitative patient-led study

Table 1  A patient-driven grounded theory of the ERAS journey

Patient experiences with an ERAS programme

<table>
<thead>
<tr>
<th>Category</th>
<th>Subcategory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overarching concept: invite me into ERAS, from diagnosis to recovery, so that I can take responsibility for my own health</td>
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<tr>
<td>Waiting and preparing for surgery: preoperative experiences</td>
<td>▶ Knowledge of ERAS</td>
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<tr>
<td></td>
<td>▶ Preoperative Information from surgeons and nurses</td>
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<tr>
<td></td>
<td>Stress:</td>
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<td></td>
<td>▶ Fears about surgery</td>
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<td></td>
<td>▶ Worry about finances, family, work</td>
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<td></td>
<td>▶ Bowel preparation and travel-related stressors</td>
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<tr>
<td></td>
<td>▶ Lack of information</td>
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<tr>
<td>Surgery and stay in-hospital: in-hospital experiences with providers</td>
<td>▶ Pain control</td>
</tr>
<tr>
<td></td>
<td>▶ Journal</td>
</tr>
<tr>
<td></td>
<td>▶ Following ERAS protocol</td>
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<tr>
<td></td>
<td>▶ Medical care and postoperative health</td>
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<tr>
<td></td>
<td>▶ Rapport with providers</td>
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<tr>
<td>Surgery and stay in-hospital: non-provider-related in-hospital experience</td>
<td>▶ Noise level</td>
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<tr>
<td></td>
<td>▶ Nutrition</td>
</tr>
<tr>
<td>Managing at home: discharge and postdischarge experiences</td>
<td>▶ Discharge information</td>
</tr>
<tr>
<td></td>
<td>▶ Biopsy test results</td>
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<tr>
<td></td>
<td>▶ Medical concerns and home help</td>
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<td></td>
<td>▶ Need for a designated contact</td>
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</tbody>
</table>

### Table 2  Key principles to guide patient engagement in ERAS

<table>
<thead>
<tr>
<th>Guiding principle</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. ‘One size will not fit all’</td>
<td>No single step-by-step process or ‘model’ for patient engagement can be developed. There is a need to recognise the different cultures and contexts within which ERAS is being implemented; the reality that patients will have different preferences regarding how they want, or are able, to be involved at every level.</td>
</tr>
<tr>
<td>2. Wherever possible, build on existing mechanisms for capturing, analysing and disseminating patient/family feedback.</td>
<td>This approach will avoid unnecessary duplication of effort and will be more cost-effective. It is recognised, however, that new data collection, analysis and dissemination approaches may be required.</td>
</tr>
<tr>
<td>3. Experiences from a broad cross section of patients should be sought.</td>
<td>Patients with either very poor or very good experiences, and those with greater resources, are more likely to provide input. In order to capture a broad range of experiences, it is important to identify and address barriers to participation wherever possible.</td>
</tr>
<tr>
<td>4. Not all illnesses or surgeries are the same, so it may be important to identify subgroups of patients that may have some unique issues.</td>
<td>Although there will be some commonalities with respect to patients’ experiences with colorectal surgery and ERAS, there may also be differences. For example, patients with inflammatory bowel disease may have some unique issues and needs compared with those with bowel cancer.</td>
</tr>
<tr>
<td>5. Priority should be given to what patients want to tell us, not just what the system wants to hear.</td>
<td>While ERAS personnel have many important questions about patient experiences, it is crucial that patients also have open-ended opportunities to talk about issues of importance to them, issues that may not be anticipated by health professionals.</td>
</tr>
<tr>
<td>6. Nursing units and the ERAS programme need to value patient feedback and expertise and be invested in ongoing learning and improvement.</td>
<td>Meaningful patient engagement requires that healthcare professionals be interested in hearing patient feedback and using it to inform changes in practice and policy. Individual health professionals need to be supported by units and facilities that are invested in and provide supports for ongoing learning and improvement.</td>
</tr>
<tr>
<td>7. Patients need to know how their input is being used.</td>
<td>Leading in, there is a need to let patients know how their input will be used, and then afterwards it is important to circle back and let patients know the impact of their input.</td>
</tr>
<tr>
<td>8. Patient engagement needs to be resourced if it is to be done well.</td>
<td>Patient insights can be a core contributor to changes in policy and practice that will result in more positive patient experiences and better outcomes. Patient engagement must be well resourced in order to optimise its value and</td>
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</table>

<table>
<thead>
<tr>
<th>Table 3</th>
<th>An ‘engaging patients in ERAS’ matrix</th>
</tr>
</thead>
<tbody>
<tr>
<td>We inform patients</td>
<td>Patients inform us</td>
</tr>
<tr>
<td><strong>Individual care level</strong> (Patients are engaged in their own care)</td>
<td>- Patients are provided with clear information about ERAS throughout the surgical trajectory, in ways that work for them.</td>
</tr>
<tr>
<td></td>
<td>- Perioperative education information is shared with patients prior to their clinic appointment so that they can ask informed questions.</td>
</tr>
<tr>
<td><strong>Unit level</strong> (Patients are engaged at the Unit level)</td>
<td>The unit supports staff in patient education activities.</td>
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<tr>
<td></td>
<td>Patients are invited to share their experience at staff meetings.</td>
</tr>
<tr>
<td><strong>ERAS initiative level</strong> (Patients are engaged at the ERAS level)</td>
<td>The development and evaluation of ERAS preoperative education modules are informed by what patients need and want.</td>
</tr>
<tr>
<td></td>
<td>- Patient research participants are meaningfully involved throughout research processes.</td>
</tr>
<tr>
<td></td>
<td>- ERAS education working groups.</td>
</tr>
</tbody>
</table>

The surgical continuum across which patients are engaged extends from diagnosis to recovery. Patients choose how they want to engage, and there is recognition that this may change over time. The knowledge and experiential expertise that patients bring, at each of these levels, is highly valued.
<table>
<thead>
<tr>
<th>Evaluation (Examples)</th>
<th>Dissemination (Examples)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>We inform patients</strong></td>
<td><strong>Game results can be tabulated and presented at staff meetings to inform local practice of patient knowledge gaps.</strong></td>
</tr>
<tr>
<td>- Trivia game online to assess patient understanding of basic ERAS guidelines and principles.</td>
<td>- A patient satisfaction survey to evaluate education activities.</td>
</tr>
<tr>
<td>- An open-ended section in journal/logbook for patients to write about their experience, which can be collected and analysed using qualitative methods.</td>
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</tr>
</tbody>
</table>

The cells of the matrix have been populated with some examples of how evaluation and dissemination of outcomes can be implemented at the individual care level. These are not meant to be recommended activities, but are simply illustrative examples of what this could look like. ERAS, Enhanced Recovery After Surgery.

Diverse, inclusive, participatory

A five-year national research project involving young people and families, which aims to improve youth mental health care in Canada.
Message from Mary Anne Levasseur, National Lead and Coordinator ACCESS Open Minds Families and Carers

As the mother of a young man with mental health concerns, I have given my all to supporting his journey through recovery. Unfortunately, too much of my energy has been wasted navigating a complex healthcare system while defending my role as his caregiver and advocate. The more contact I had with other family caregivers, the more I came to realize that we all face similar challenges.

Sharing information, talking, and listening help. But change at the societal and political level is necessary to re-engage families. We at AFC are working to give families a better chance at helping their youth, themselves and others. Please join us.

http://accessopenminds.ca/
The 5 ACCESS Open Minds objectives

Central to the ACCESS Open Minds framework are the overarching 5 objectives:

- Early Identification
- Rapid Access
- Appropriate Care
- Youth & Family Engagement
- Continuity of Care Beyond the Age of 18

14 sites across 6 provinces and 1 territory implementing the ACCESS Open Minds framework in youth mental health

http://accessopenminds.ca/
http://accessopenminds.ca/
Who “owns” resilience in health care?

The patient always leads

... but we travel together

“... NOW MAKE IT SO!”
Thank you!

carolyn.canfield@ubc.ca