The Patient's Voice and What We Do with What They Say

Donna L. Berry, PhD, RN, AOCN, FAAN
PSONS Symposium
February 21st, 2014

---

Bottom line first

Creating opportunities (and an environment) for individuals with cancer to fully express themselves regarding healthcare issues and participate fully in their own healthcare

---

The case of cancer-related fatigue

- Mrs. Lee, a 52 year old mother of two teenagers, has just completed autologous stem cell transplant to treat her diagnosis of non-Hodgkin's lymphoma. She is seen by her nurse in the DFCI lymphoma clinic for a 30 day follow up and is describing serious fatigue. She wakes up every morning already tired, is unable to carry out tasks around the house and feels that she sits on her couch for most hours of the day.

- What should you recommend?
- How will you know if it works?

---

The Best Intervention

- The best intervention for a patient-reported issue or concern is based on scientifically-sound research, your patient’s particular needs and preferences, and the feasibility of that intervention in your practice.

- The result of putting this all together with your own expertise is an essential component of oncology nursing practice and patient care excellence.

- Professional groups and experts have called this “evidence-based practice.”

And so….what next?
Why is EBP important for oncology nurses to use in clinical practice?

- To use clinical expertise with best practice evidence for competent knowledge, skills, and abilities in delivering quality and safe patient care.
- To eliminate time and money wasters

Getting started

What exactly is the issue and how do we want it to be different?

Back to your patient's fatigue

Clinical Question

Do we have a policy/pathway?

- Yes
- No

Quality Improvement

EBP

Generate new knowledge

How to improve cancer-related fatigue?

Is there evidence to guide a practice change?

How can we improve or adhere to the policy?

Goals of EBP, QI & Research: Understanding the difference

- Evidence Based Practice
  - Integrate the best available scientific evidence into practice to improve patient outcomes.
- Quality Improvement (QI)
  - Develop institutional systems and processes to improve outcomes.
- Research
  - Investigate and develop new scientific knowledge to improve outcomes.
Using Science to Guide Clinical Practice

- Assure existing patient care routines are safe and effective
- Eliminate practice routines which do not enhance patient care in terms of outcomes or safety
- Adopt well-tested, new interventions in order to provide the best possible care

BUT....

- A minority of nurses and health care professionals actively engage in, or study application of, Evidence Based Practice
  - Only 21% of 1200 nurses had implemented evidence from a research study in the last 6 months (Bostrom & Suter, 1993)
  - About 33% of the time, health care providers do not follow practice guidelines or best evidence (Cretin et al., 2001)
  - It takes about 17 years for a robust clinical trial finding to become standard of care (Balas & Boren, 2000)
  - Despite focus on EBP over the last decade, Evensen et al. (2010) reported that the number of implementation trials has not increased for evidence-based medical interventions
  - EBP is valued but not consistently implemented (Melnyk et al, 2012)

Barriers

- High value for individual decisions and practice
- Health services and care factors
  - Poor administration/management
  - Sociodemographic factors
  - Staff skills
  - Patient’s environment

The Disconnect

- No easy answers
- No “bridging the gap”
  - Scrap the gap
  - If we bridge it, the gap stays there.
Examples from Oncology

• Borneman et al. (2010) at City of Hope evaluated implementation of NCCN Guideline-based, pain & fatigue intervention: "Passport to Comfort."
  - Educational and system changes
  - 187 patients with scores > 4/10
  - Significant improvements in outcomes; sustained for 3 months

Examples from Oncology

• At the SCCA, a pan-alliance committee of nurses tackled problems associated with discharge medications in the transition from inpatient to ambulatory care (Berry et al., 2014)
  - Pre-post test of an intervention including a post-discharge, follow up RN phone call plus written instructions.
  - Significant improvement in adults with regard to self-reported medication names, doses, frequencies and routes of administration and purposes.

Examples from Oncology

Oral chemotherapy adherence

  Sommers et al. (2011) evaluated the feasibility of using multi-professional education, a nurse-led follow up telephone call and use of medication diaries to enhance patients’ self-reported medication adherence and knowledge of oral chemotherapy
  - At the end of the first cycle of therapy, MMAS-8 adherence scores were high in the 30 participants, mean of 7.89 (SD=.55).
  - Seventeen participants documented side-effects within the first 72 hours of initiation of treatment; with 8 participants needing further assistance with management of the side-effects.
**SPAWN Group**

Create the project team
- Typically a subset of the SPAWning group
- Champion(s) – lead & contact
- Target(s) – direct care clinician
- Sponsor – decision maker who can provide resources (e.g., release time)
- Facilitator – advanced practice/researcher with knowledge of methods

Kitson et al., 2008

---

**The PICO (T) question**

- Derived directly from your practice
  - P = patient population
  - I = intervention or area of interest
  - C = comparison intervention or group
  - O = outcome
  - T = time

Melnyk, et al 2009

---

**The PICOT question in oncology**

<table>
<thead>
<tr>
<th>Population</th>
<th>Intervene</th>
<th>Compare</th>
<th>Outcome</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adults on oral chemo</td>
<td>F/U educational phone call</td>
<td>Clinic only teaching</td>
<td>Adherence</td>
<td>Initial 3 months</td>
</tr>
<tr>
<td>Patients at risk for mucositis</td>
<td>Systematic oral care protocol</td>
<td>Rx solution only</td>
<td>Mucositis severity</td>
<td>Acute care period</td>
</tr>
</tbody>
</table>

---

**Find the strongest evidence**

<table>
<thead>
<tr>
<th>Author &amp; year/ Level of Evidence</th>
<th>Design &amp; groups</th>
<th>Sample</th>
<th>Intervention</th>
<th>Results</th>
<th>Conclusions</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adamson, 2009 RCT</td>
<td>Exercise v. relaxation v. massage</td>
<td>N=269 mixed dx Europe</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Critically appraise the evidence

- Are the methods of studies believable; is there sufficient information to tell?
- What are the results? Are they meaningful and reliable—if applied, might I get the same results?
- Are the findings clinically relevant to my patients?

To implement or not?

- Addressing the sufficiency of the evidence
  - Consider institutional priorities
    - Formularies do this often
  - Consider individual preferences
  - If implemented, careful process

Implementation

- Define process and variables
- Define stakeholders and communicate
- Begin small and simple
- Measures planned
- Unit coordinators

Evaluate the outcomes of implementation

- Measure and monitor in one’s own setting
  - Panels of patients
  - Access already collected databases
  - Create new outcome measures
Diving deeper into the evidence

1. Fatigue
2. Anorexia
3. Medication adherence
4. Decisional conflict

Where’s the E? - Fatigue

• Pharmacologic
  • Methylphenidate, a sympathomimetic psychostimulant, has shown efficacy in two trials
  • Modafinil, one trial in cancer, only effective in patients with severe fatigue. Positive trial in HIV/AIDS
  • Bupropion, a norepinephrine dopamine reuptake inhibitor, two positive trials.

Where’s the E? - Fatigue

• Psychosocial Interventions show promise
  • Cognitive behavioral therapy, supportive-expressive therapy, behavioral therapy, counseling, educational training, and restorative training
  • Mixed results

Exercise studies predominately positive
• Exercise with aerobic and strength training components was found to be more effective in reducing CRF than aerobic exercise alone
• Supervised exercise was found to be more effective than home-based exercise
• Cochrane review concluded that aerobic exercise can be regarded as beneficial for individuals with cancer-related fatigue during and post-cancer therapy, specifically in solid tumors.

One systematic review (Minton, 2010)

One systematic review (Minton, 2010)

(Meta-analyses (Jacobsen, 2007; Kanga, 2008; Cramp, 2012)
Where’s the E? - Anorexia

- Pharmacologic
  - Megestrol acetate
    - Increases appetite and small weight gain
    - Increased risk of blood clots, fluid retention resulting in swelling of the feet or hands
  - Neutroceuticals
    - Oral fish oils that contain the omega-3 fatty acid eicosapentaenoic acid (or EPA) to stabilize weight loss and promote weight gain
    - No conclusive evidence

Cochrane reviews (Dewey, 2007; Ruiz Garcia, 2013)

Where’s the E? - Anorexia

- Non-Pharmacologic
  - Evidence suggests that dietary advice (nutrition counseling, with or without oral nutritional supplements, may improve weight, body composition and grip strength…. no evidence of benefit of dietary advice or oral nutritional supplements given alone or in combination on survival.
  - The better the nutritional status, the higher the self-reported quality of life.
  - The question remains how to get to “better nutritional status”

Cochrane reviews (Ruiz Garcia, 2013); Lis, 2012

Where’s the E? – Medication Adherence

- Psycho-educational strategies are effective
  - Discharge teaching
  - Monitoring of symptoms and adherence
  - Prompting
- Procurement assistance

Cochrane review (Hayes, 2008); Berry, 2014; Winklejohn,2010; Schneider, 2011; Sommers, 2012

Where’s the E? – Medication Adherence

- Discharge teaching
  - Determine patients’ and caregivers’ understanding of discharge medication regimens following a hospital stay
  - Oncology patients of any diagnosis discharged from UWMC to ambulatory care at SCCA
  - Pre-post design
  - Intervention
    - Medication Reconciliation
    - Post Discharge Teaching Telephone Call

Berry, Cunningham, Eisenberg, Wickline et al. , 2014;
Where’s the E? – Medication Adherence

- Discharge teaching
  - Significant improvements in patient reported knowledge of medication
    » Name
    » Dose
    » Route
    » Frequency

Berry, Cunningham, Eisenberg, Wickline et al., 2014;

Where’s the E? – Decisional Conflict

“Let me tell you what you need to know”

“Let me set you up with some information”
• About 50% of women in the US do not receive guideline and evidence-based therapy for ovarian cancer; therapy that leads to significant survival advantages.
• They do not go to gynecologic-oncologists, do not receive adequate surgical staging and do not receive adjuvant chemotherapy.
• Why not?
• Not informed about options; distance, economics

Where’s the E? – Decisional Conflict

• Decision aids reduce conflict and regret in women deciding about breast conserving surgery vs mastectomy

Waljee, 2007; Lam, 2013
**The Personal Patient Profile-Prostate (P3P)**

A decision support system to prepare a man to engage in shared decision making with a consulting health care provider

**RCT Multi-site Trial**

- Seattle
  - UWMC/SCCA
  - VA
  - Seattle Prostate Institute
- Philadelphia –FCCC
- Augusta Georgia-Medical College of GA
- San Antonio- Univ of TX and VA

NINR 2006-2009

**Coaching customized to race and age**

Decisional control coaching video

**Our results**

- The intervention had a beneficial effect; reducing decisional conflict
  - Men receiving the P3P intervention reported significantly less conflict six months after the on-study consult visit.
- Differences in men at the various study sites
  - At baseline, men of minority race and ethnicity and those who were not home Internet users were not as conflicted and thought they knew what to do
  - Yet, the strongest effect of the intervention was at such sites

Berry et al, 2013

NINR 2006-2009
Bring it back

• What to do with our findings to MAKE a DIFFERENCE?
• What will you do?
• Will you SPAWN?

The Disconnect

• Will you “scrap the gap”?

Finally

Knowing is not enough; we must apply
Willing is not enough; we must do

Von Goethe

Bibliography

• Berry et al., Improving Patient Knowledge of Discharge Medications in an Oncology Setting. CJON. In press. Accepted Oct 2013
<table>
<thead>
<tr>
<th>Reference</th>
<th>Title</th>
</tr>
</thead>
</table>