



www.jeffbelkora.com/evidence

List of references to literature

www.jeffbelkora.com/thanks

Sources of inspiration and support

The Patient Support Corps: An innovative staffing approach to support patients in shared decision making

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Partnering with Patients to Drive Shared Decisions, Better Value, and Care Improvement

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Quantum Leap Healthcare Collaborative

The Cancer Support Community

Information and communication **needs** of patients

- At diagnosis: “Too much, too little, conflicting **information**”
- During visit: “I forgot to ask **questions** that were keeping me awake”
- After the visit: “I can’t **recall** – it all went in one ear and out the other”



**2004: Who can deliver
decision and communication aids
in the UCSF Breast Care Center?**

Interns!



2005



2006



2007



2008

2009



2010



2011



2012

Tasks to support patient needs

Before Visit

1. Send decision aids



2. List questions

Example Question List (to identify energy)
 I used a portable computer at a DCIS Decision Services session (created a word-generated list of questions and answers by reviewing and paraphrasing the patient's verbal responses during a computer-generated conversation). The questions, organized by the Patient Care Coach's patient's request, are printed copies of the patient's questions, concerns, and the physician or nurse's replies and during the appointment.

QUESTIONS
 • Was diagnosed with breast cancer in August and had surgery in March. Followed by radiation. Is my understanding of the radiation correct as per my doctor's explanation?
 • Radiation: Additional additional treatment?
 • Surgical margin: How often? How often does that mean it is 1.5 cm around edges?
 • Radiation: How often?

CHANGES
 • If breast chemotherapy, what are the options?
 • Decision: When will chemotherapy?

PROBLEMS
 • Avoid side effects such as weakness, hair loss, infections. I am concerned about fatigue and general loss of energy. Is it safe to do a lot of walking or exercise?
 • I am not up doing a lot of walking or exercise. I want to get a job as a teacher to become a 1 can go back to work as a teacher.
 • What resources are there? I want to receive walking of 2 can to receive chemotherapy. I walk with a dog. Can you recommend any resources or services provided by chemotherapy?
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PEOPLE
 • Can I get DCIS decision services closer to home? Are there any local resources? Do I have local resources?

EXAMPLE
 • I am not up doing a lot of walking or exercise. I want to get a job as a teacher to become a 1 can go back to work as a teacher.

EVALUATION
 • In a few weeks to receive chemotherapy (probably) with a longer period of time? Would prefer receiving chemotherapy in my 1.5 cm area?
 • Are there any other options? Are there any other options? Is general delivery an option?
 • If I get chemotherapy?

RECOMMENDATIONS
 • I am not up doing a lot of walking or exercise. I want to get a job as a teacher to become a 1 can go back to work as a teacher.
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During Visit

3. Take Notes



4. Make audio-recording



After Visit

5. Burn CD



6. Print notes

Example Question Summary (to identify energy)
 Using a portable computer and digital audio-recorder, a DCIS Decision Services assistant asked notes and recorded the consultation. Afterward, the assistant created a word-generated summary of the patient's responses to the patient's questions. The assistant gave a copy of the consultation summary to the patient, along with a computer-generated word-generated summary of the patient's questions, concerns, and the physician or nurse's replies and during the appointment.

SITUATION
 Following a visit, the patient brought through their consultation and service history notes. The patient brought a 1.5 CD, which was 1.5 cm.

CHANGES
 • No chemotherapy.
 • Decision: How often, radiation weight, exercise.
 • Decision: How often, radiation weight, exercise.
 • Decision: How often, radiation weight, exercise.

PROBLEMS
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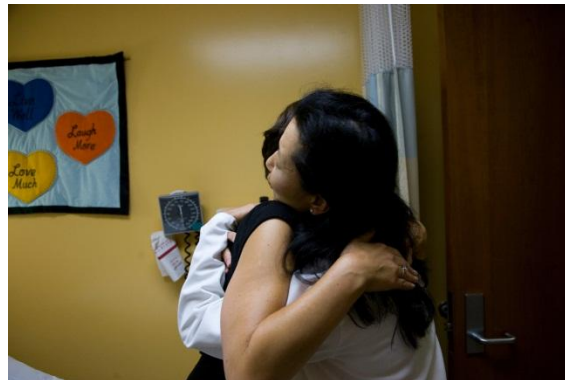
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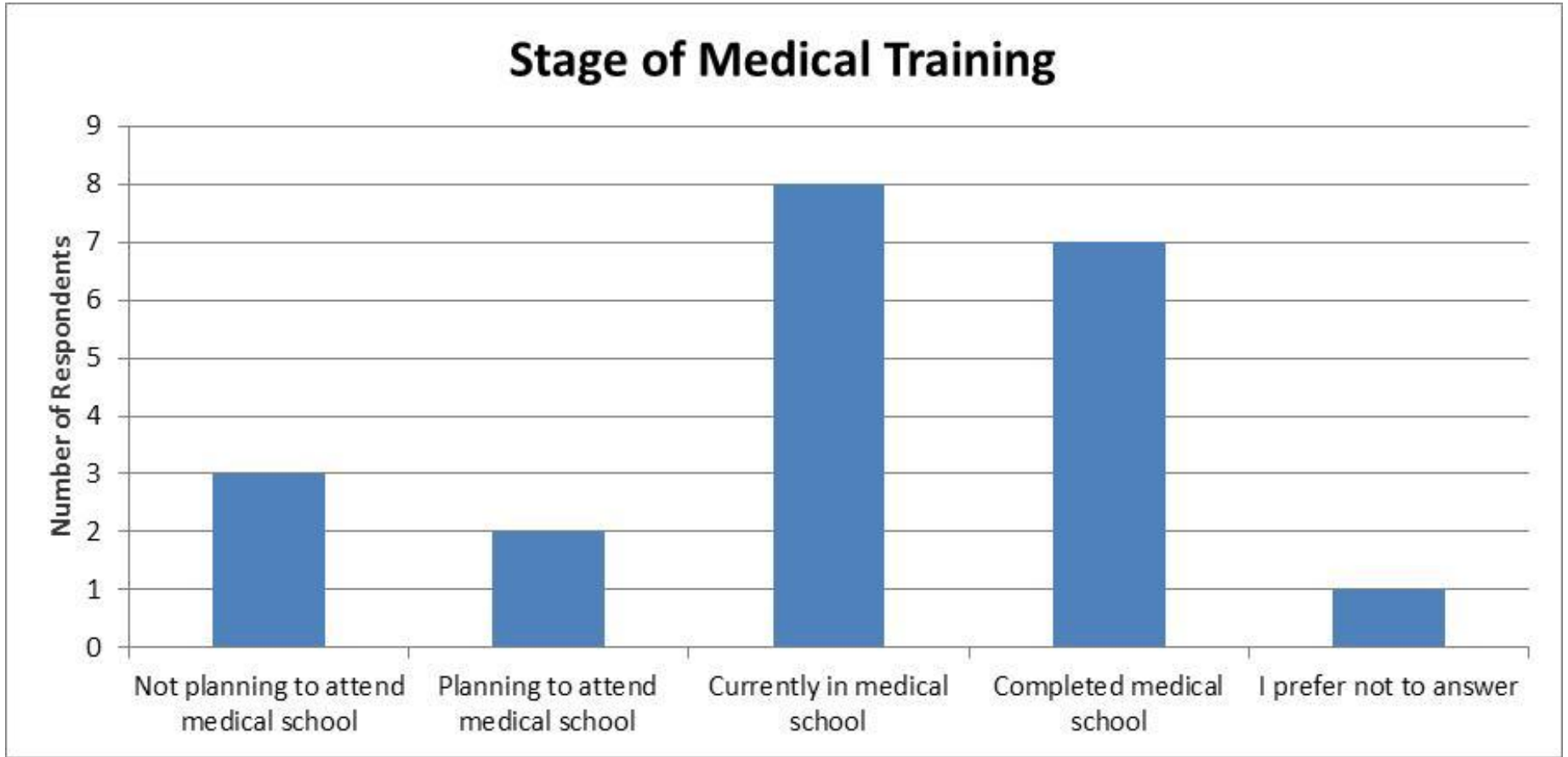
Patient reactions

- “This was exactly the material I was looking for all over the web, but having a hard time finding in a consolidated format that made sense...”
- “It was hugely helpful to have my questions prepared beforehand ...
- “The recording and notes were invaluable in filling in the parts of the conversation that were hard for us to remember...”



“Do you think I’m going to die?”

Survey of 47 alumni



Survey responses – lessons learned as intern

“Decision Services helped me actually learn the art of listening through practice, patience, and silence.

“I learned to silence my own voice and let the content of the patient and the physician guide my own work.”

Survey responses – lessons retained as MD

Now as a doctor... I believe the core values I developed are still there: a non-judgmental attitude, careful approach to humor, and an avoidance of saying things that I truly can't control ("everything is going to be okay," etc).

How can we **expand** this program?

From the UCSF Breast Care Center...

...to other UCSF clinics...

...to other UC Medical Centers

... to other clinics around the US and around the world...

Solution: student and other volunteers?



The image is a screenshot of the University of California Berkeley website. At the top left is the Berkeley logo with the text 'UNIVERSITY OF CALIFORNIA'. To the right of the logo are navigation links: 'MOBILE | MAP | CALMAIL | SEARCH:'. The search bar contains the text '3,000 premedical students', which is circled in red. Below the search bar are links for 'Berkeley web', 'Directory', and 'News Center'. A horizontal menu below that includes 'Students | Prospective students | Faculty | Staff | Cal Parents | Alumni'. On the left side, there is a vertical navigation menu with categories: 'About Berkeley', 'Applying to Berkeley', 'Academics', 'Research', 'Teaching', 'Working', 'Campus life', 'Public service & community', 'Visiting & getting around', and 'Administration & services'. On the right side, there is a list of links: 'Schools, colleges & departments', 'A-Z index of websites', 'Academic calendar | Events', 'Courses (General Catalog)', 'Schedule of classes | Summer', 'bSpace | TeleBears | BearFacts', 'International students & scholars', 'Jobs | Career Center', 'Diversity, equity & inclusion', 'Libraries | Museums', 'Computing | Blu', 'Bookstore | Cal gear | Rec Sports', 'Health services (Tang Center)', and 'Emergency preparedness'. At the bottom right, there is a banner for 'The CAMPAIGN for BERKELEY'. In the center of the page is a photograph of a busy campus walkway with many students. A 'Photo info >' link is visible at the bottom right of the photo.

Patient Support Corps - Strategic Direction

- Purpose
 - Patients are informed and involved in their treatment decisions.
- Vision
 - All patients have the support they need to be informed and involved.
- Mission
 - Provide **students and other volunteers** to assist patients .

Value Proposition for The Patient Support Corps

- ✓ Low-cost extension of workforce: admin costs only
 - Costs can be shared between clinics and colleges
 - Workforce innovation (task-shifting, tapping underused source of labor)

- ✓ Improved marketing/competitiveness for clinics and colleges

- ✓ High leverage: benefits for patients and students
 - Patient satisfaction, increased knowledge, question-asking, recall
 - Student service learning: ACGME competencies

Next Steps

We foresee a three year startup period during which we will:

- **recruit early members to the network;**
- **launch service and product offerings;**
- **refine our business model**

We seek funding and other partners to support this expansion.