

ACHIEVING PATIENT CENTERED CANCER CARE

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Special thanks



Patient centered care

- First defined by IOM in *Crossing the Quality Chasm*, 2001
- Providing **care** that is respectful of, and responsive to, individual **patient** preferences, needs and values, and ensuring **patient** values guide all clinical decisions.

- Translated to a focus on shared decision making for addressing many health issues
 - Involving patients makes sense
 - Associated with more decision satisfaction and less regret
 - May be a way to reduce overtreatment (?)



The landscape of healthcare is changing

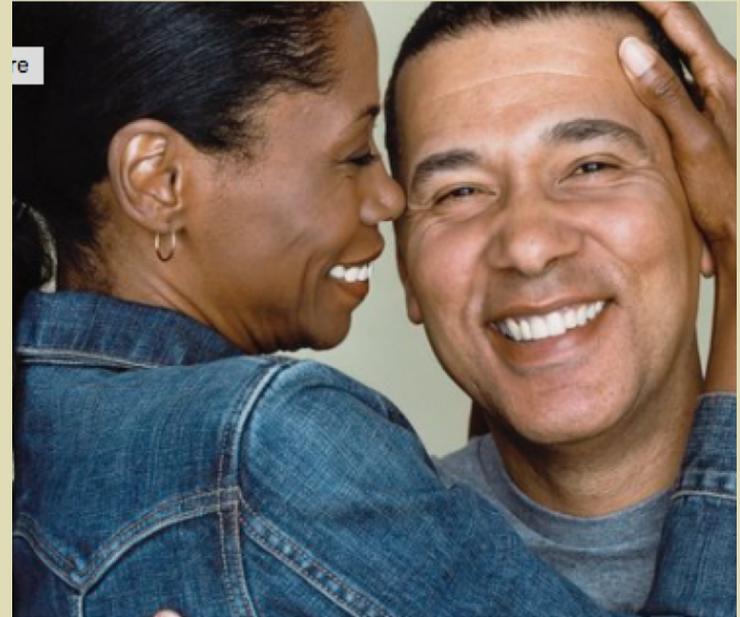


The advent of precision medicine offers both opportunities and challenges

- More testing and treatment options
- More tailored and personalized treatment possible
- More complexity to decision making

Examples

- Mr. Smith is a 58-year old with a new diagnosis of early stage, “low risk” prostate cancer. He is eligible for active surveillance, but genomic testing done indicates he is at medium risk for his cancer to spread in the next 5 years. He wants to avoid the side effects of surgery but thinks he will be too worried to “leave the cancer there”.



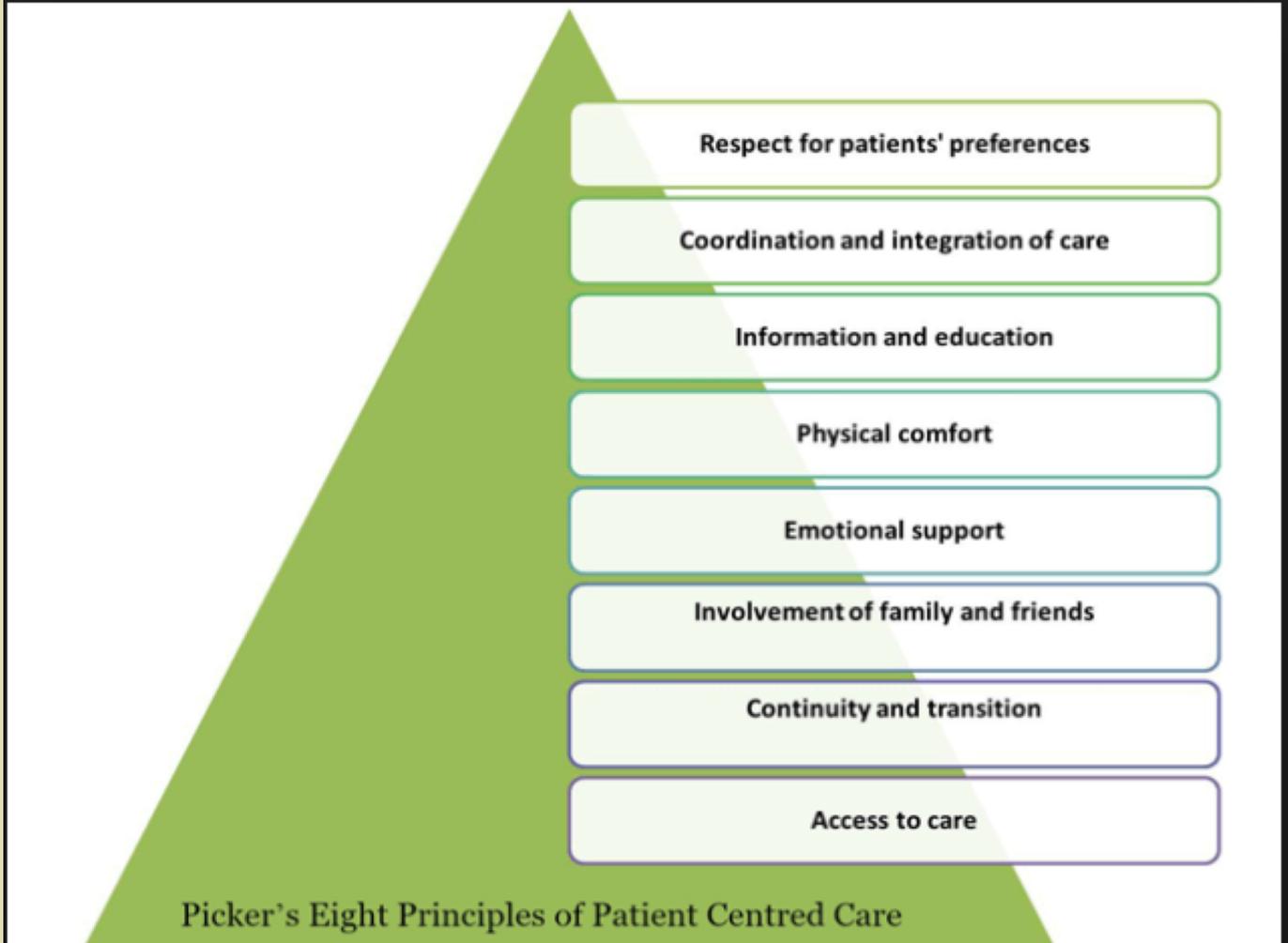
- Mrs. Landry is a 54-year old with a new a diagnosis of ductal carcinoma in situ. She receives an MRI suggesting a suspicious mass in her non-affected breast that makes her consider contralateral prophylactic mastectomy (CPM). She knows this is a big procedure but desires to achieve “peace of mind”.



- Mr. Frank is a 51-year old who has been recommended to have gene panel testing due to a family history of breast and ovarian cancer, though he does not have cancer himself. He has two teen age daughters. He is considering being tested but unsure about what the results may mean for him or his family.



- How can we provide patient centered care in the era of increasing complexity in decision making?



Respect for patients' preferences

Coordination and integration of care

Information and education

Physical comfort

Emotional support

Involvement of family and friends

Continuity and transition

Access to care

Picker's Eight Principles of Patient Centred Care

To deliver patient centered care...

4 Key areas in particular:

- Information & education
 - Respecting preferences
 - Addressing emotions
 - Involvement of others
- } High quality decision

Breast cancer treatment

- Biological variation in cancer progression
- Many different decisions across the continuum
 - Surgery type, radiation
 - Systemic treatment, neoadjuvant therapy
 - Genetic and genomic testing
- Decisions made within the first few weeks have long lasting consequences (employment, finances, QoL)
- Multi-modal therapies directed by different specialists

What do we know?

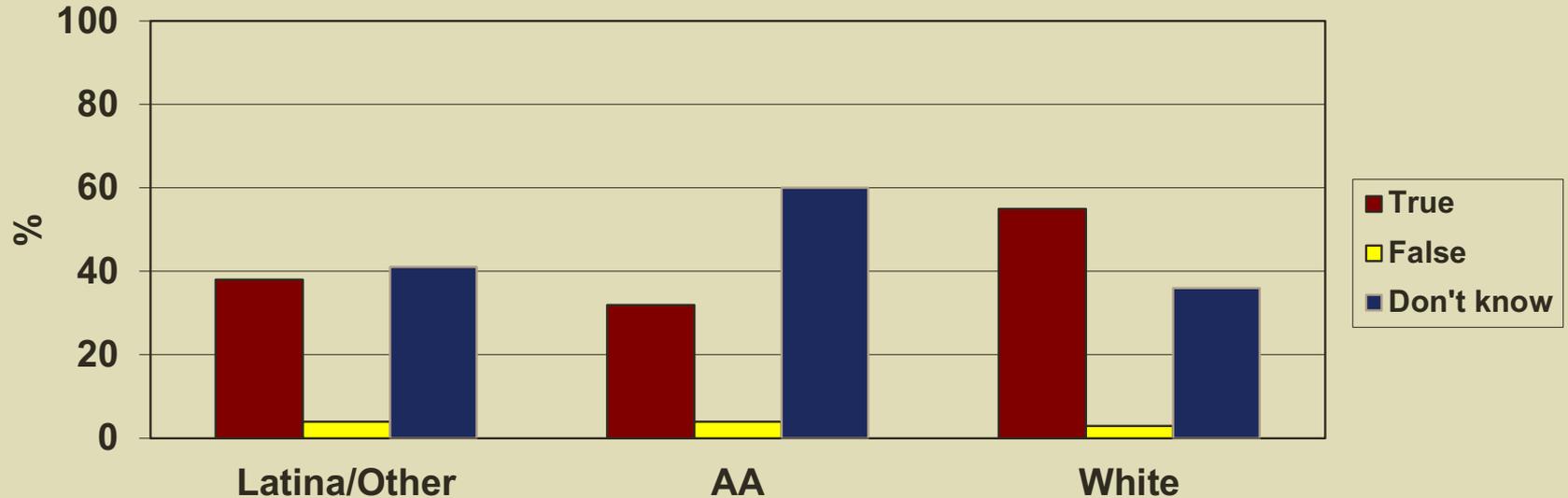
- Shed some light using data from:
 - Two population based studies
 - Intervention work

Study 1: Design and data collection

- 3,252 women diagnosed with breast cancer in Detroit & Los Angeles SEER from 7/05-2/07
- Patients surveyed about 6 months after diagnosis and again 4 years later. African American and Latina patients oversampled
 - 6 months N = 2,290 (73%)
 - 4 years N=1,532 (68%)
 - Spanish surveys sent to those with Spanish surnames
- Patient survey and SEER data merged

Knowledge is low

5 –year Survival is the same for lumpectomy + radiation as it is for mastectomy

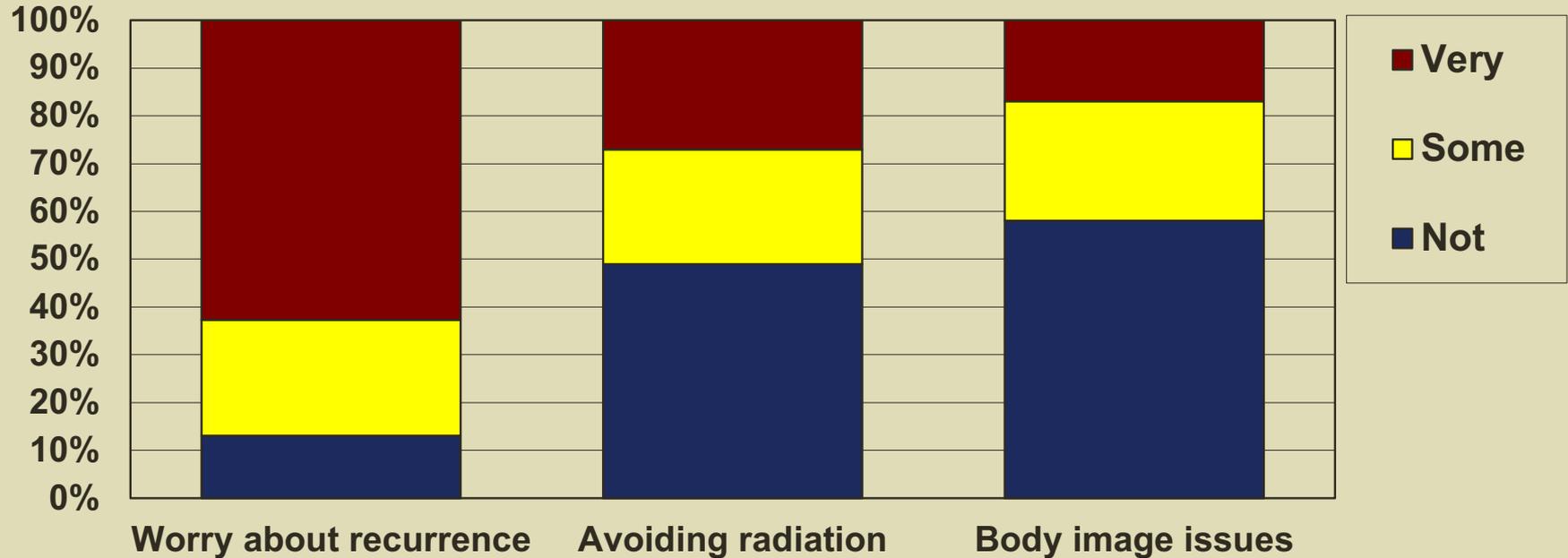


Source: Hawley et al., 2008; $P < 0.001$ for differences among race/ethnic groups

See also: Rosenberg et al., 2013; Lee et al., 2012; Sepucha et al., 2010

Women value different things

Importance of Factors When Making Surgery Decision

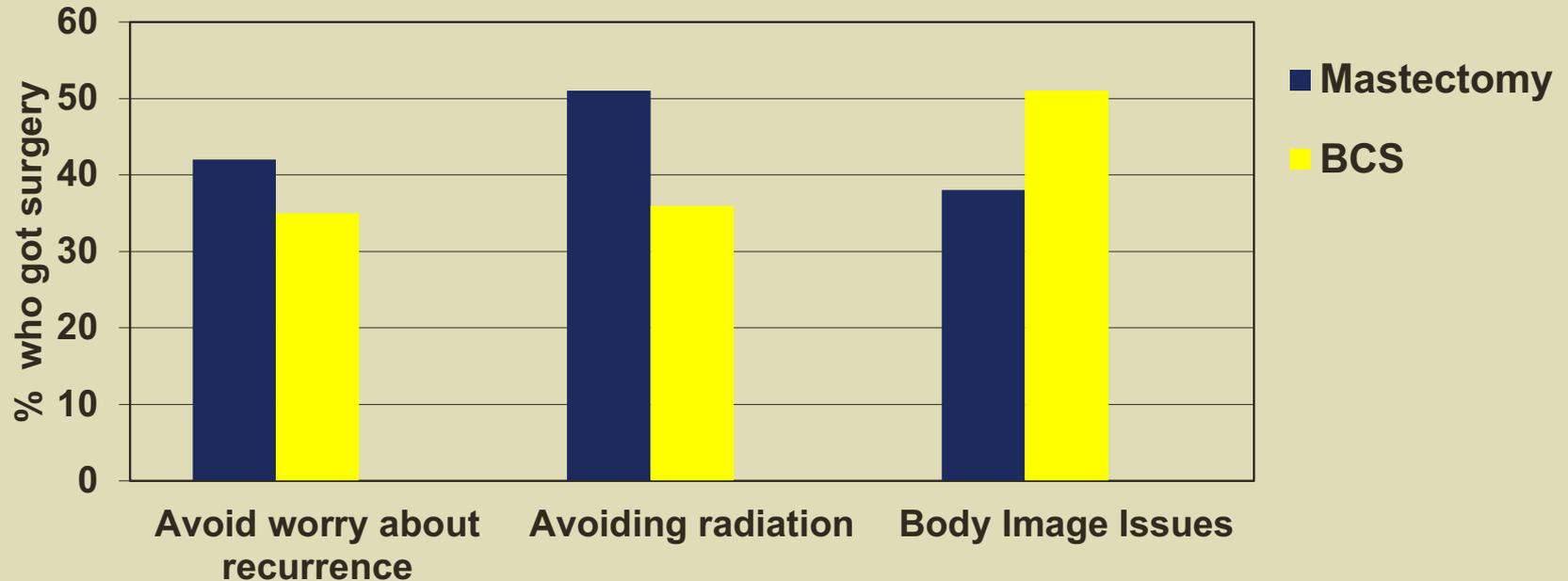


Source Hawley et al., 2009

See also: Sepucha et al., 2012, Collins et al., 2009

Values are associated with choices

Factor was very important in treatment decision making



Summary

- Knowledge about treatment risks and benefits is low, even after surgery
- There is variation in what women value, and these values relate to treatment choices

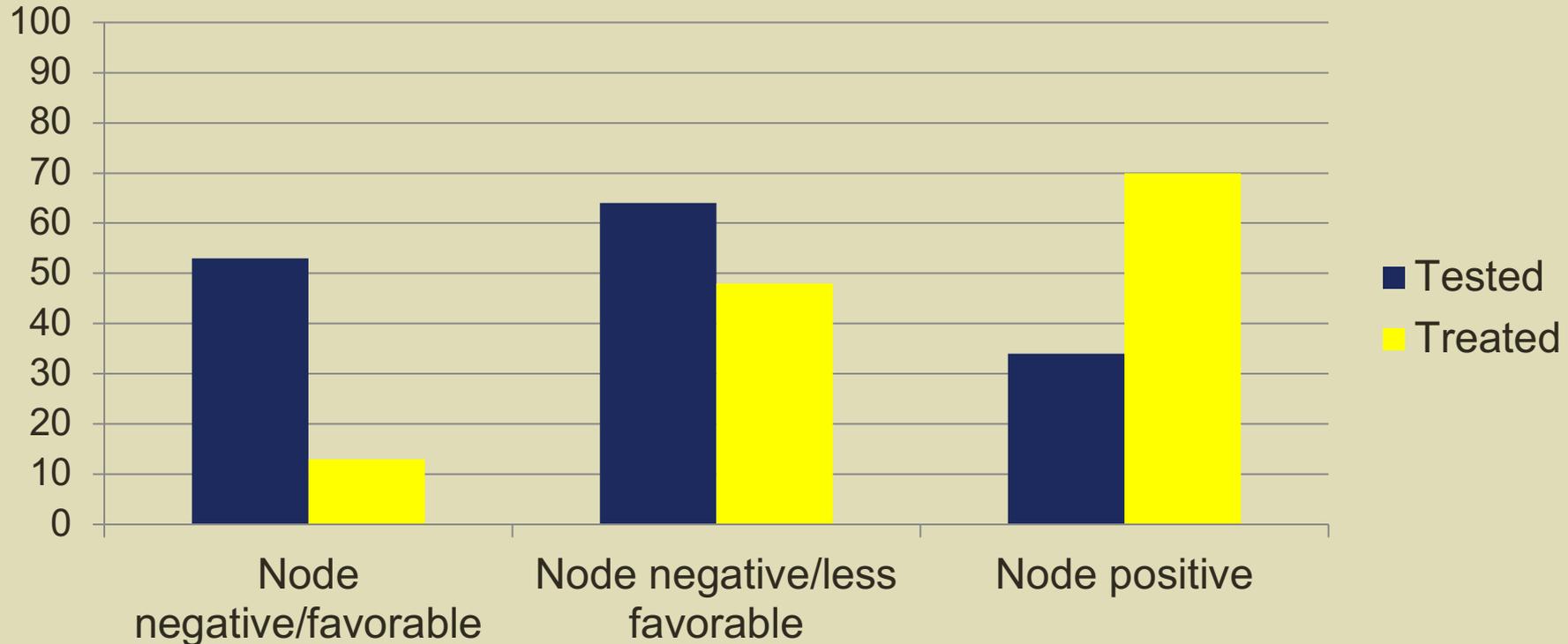
Recent Trends

- Dissemination of 21-gene assay (Oncotype) testing into clinical practice to direct chemotherapy decisions, with intended goal of reducing the burden of chemotherapy
- Increased requests for and receipt of genetic testing, both BRCA1/2 and gene panel testing
- Rise in the use of more extensive surgery for treatment (contralateral prophylactic mastectomy, CPM)
 - Most women who get CPM are at average risk for a 2nd primary (Hawley JAMA Surgery 2014; Kurian JAMA 2014; Tuttle JNCI 2014)

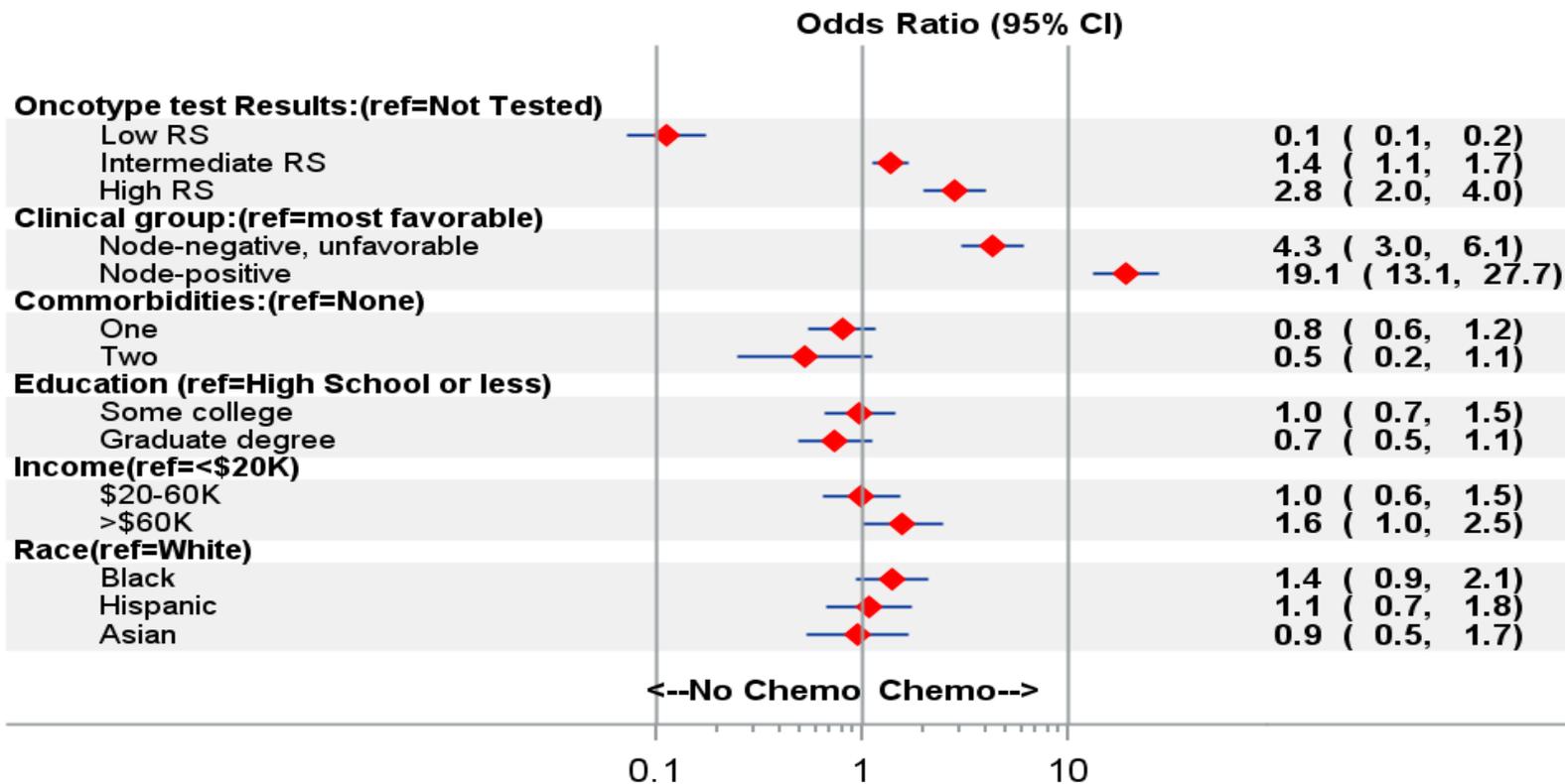
Study #2: iCanCare Study

- NCI-funded Program Project Grant (P01), “The Challenges of Individualizing Treatment for Breast Cancer” (S. Katz, PI)
- Population-based survey of 5,200 breast cancer patients from LA metropolitan and the state of Georgia SEER registries
 - African American and Latinas oversampled
 - Sampled to enrich favorable prognosis
- Data from first 2,300 (phase 1) surveyed about 6 months after diagnosis, from 5/13-9/14 or 2,900 (phase 2) from 9/14-10/15

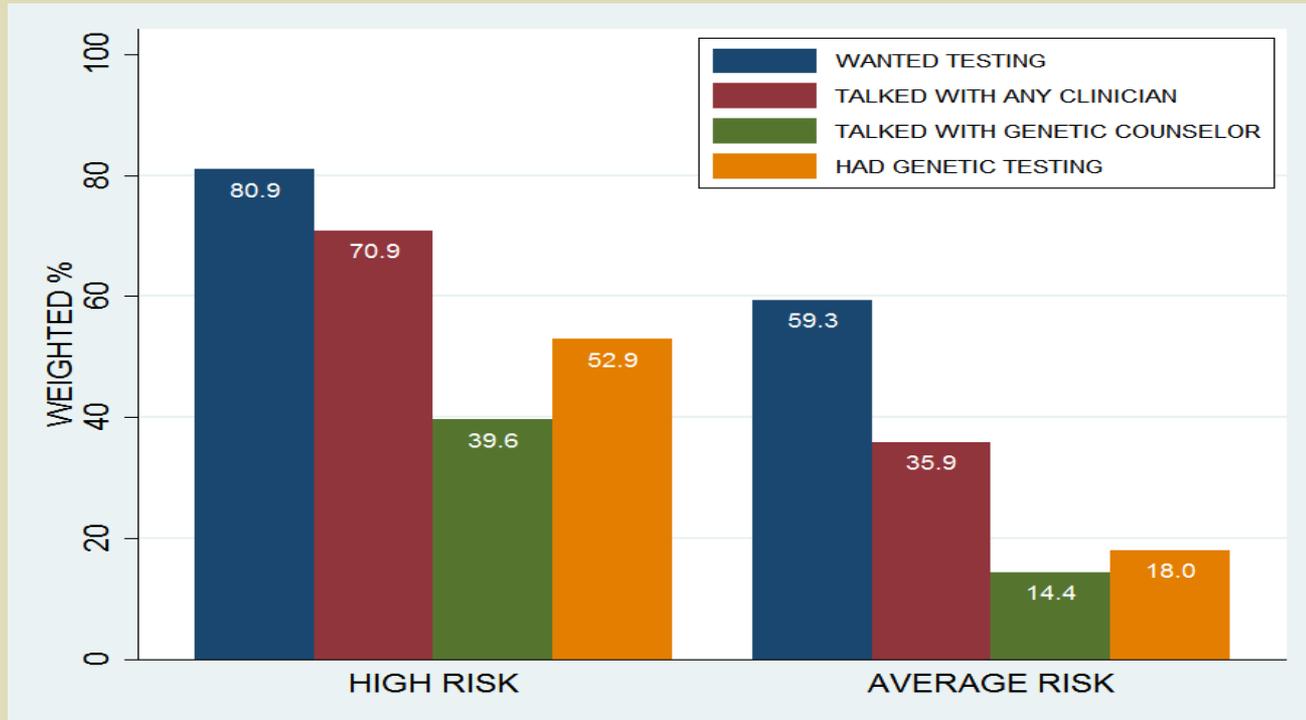
Oncotype testing and chemotherapy treatment by clinical subgroups



Correlates of Chemotherapy Receipt

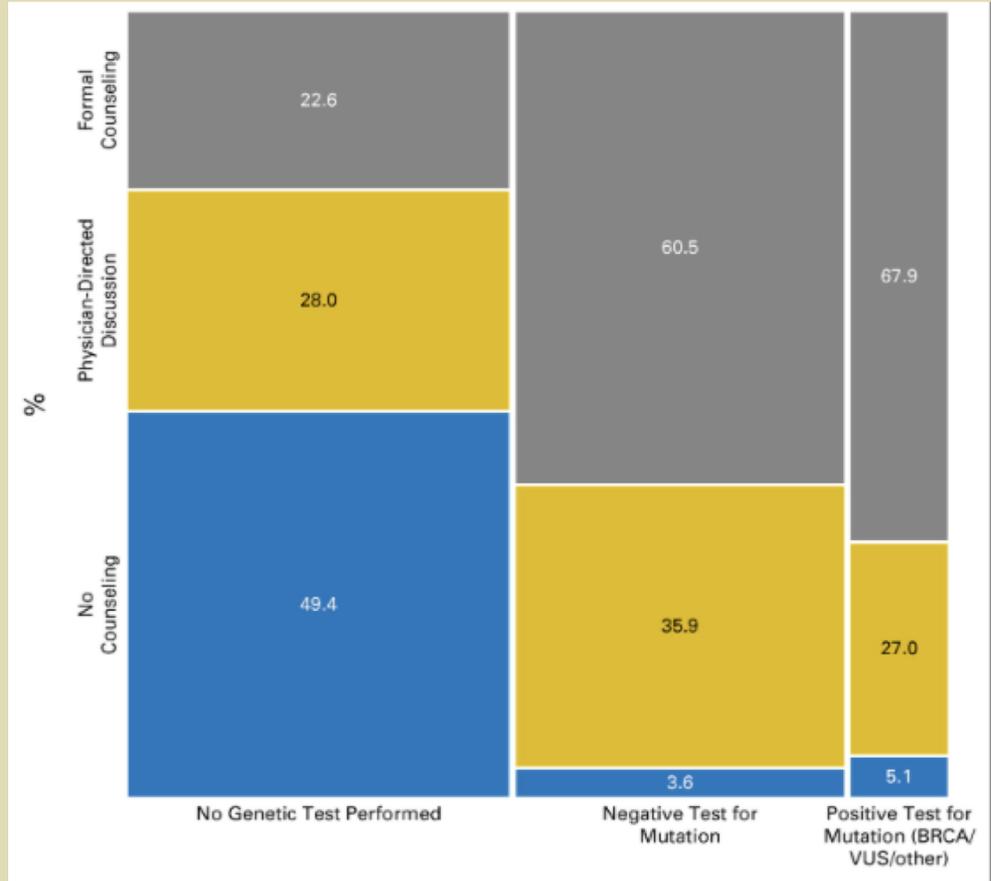


Patterns of Genetic Testing



Risk of genetic mutation

Genetic counseling by test results



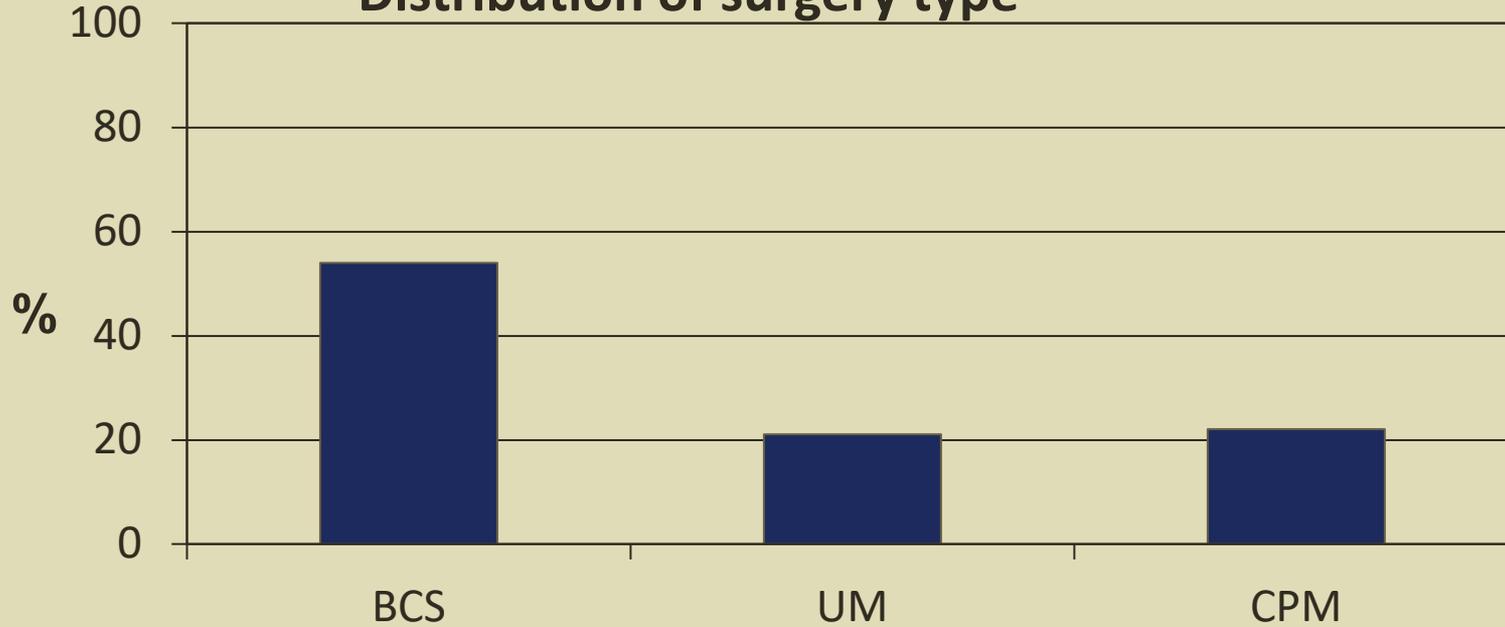
Source: Katz et al, JCO 2016

Summary

- Increased use of evaluative testing breast cancer:
 - 21-gene assay test low and high risk score maps well to treatment recommendations and use
 - Less clear about intermediate risk score
 - Genetic testing use maps to risk groups, though average risk patients are getting tested
 - Strong interest in genetic testing across risk groups, yet there remain gaps in discussion of testing with clinicians and genetic counselors. Formal counseling most common in those with mutations.

Surgery type

Distribution of surgery type



* 5 Women with bilateral cancer excluded

Source: Jagsi et al,
JAMA-Surgery 2016

Patient involvement and CPM

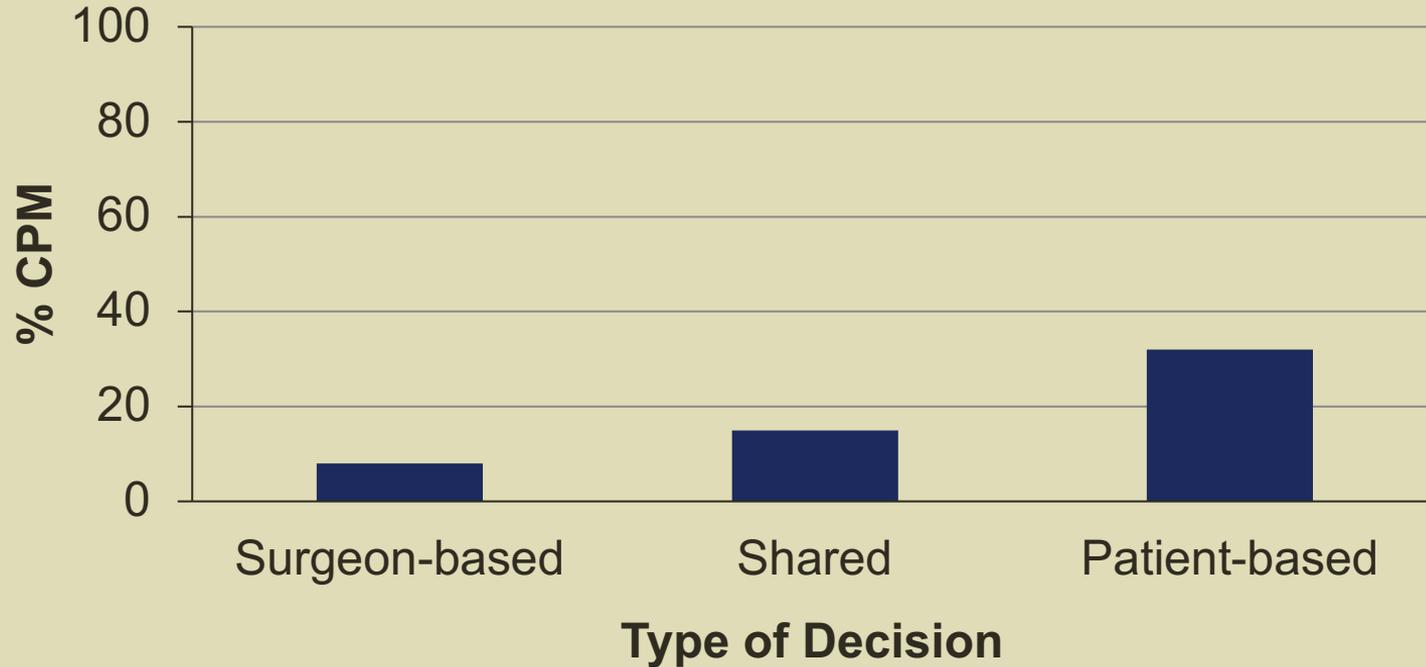


Table 3. Impact of Test Results on Prophylactic Mastectomy Outcomes

Genetic Test Result	Patient Strongly Considered Prophylactic Mastectomy ^a	Surgeon Recommended Prophylactic Mastectomy ^a	Patient Received Prophylactic Mastectomy ^a
<i>BRCA1/2</i> pathogenic variant (n = 64)	80.3	51.4	79.0
Other pathogenic variant ^b (n = 24)	39.8	10.3	37.6
VUS only (n = 198)	38.8	14.4	30.2
Negative (n = 1030)	43.7	14.1	35.3

Abbreviation: VUS, variant of unknown significance.

^a Weighted percent consideration, recommendation, and receipt of prophylactic mastectomy: all $P < .001$.

^b The other genes in which patients had pathogenic variants were *APC* (2), *ATM*

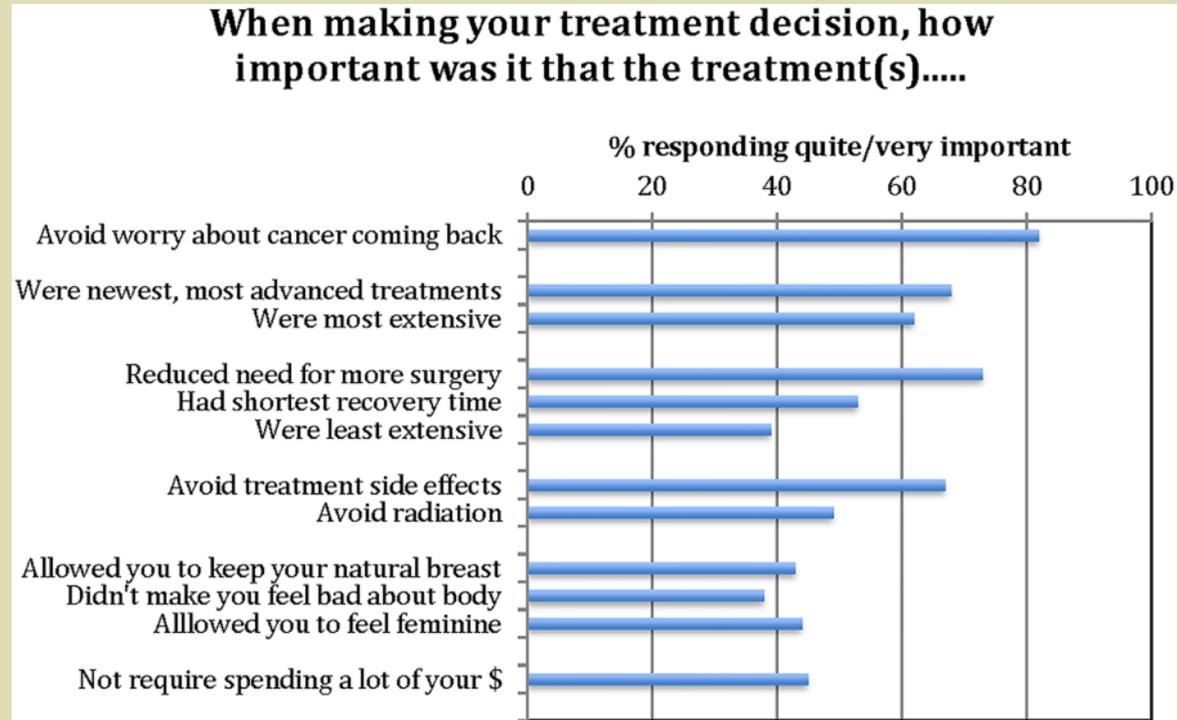
(3), *BARD1* (1), *BRIP1* (2), *CHEK2* (4), *MLH1* (1), *MSH6* (1), *NBN* (1), *NFI* (1), *PALB2* (3), *PMS2* (2), *RAD50* (1), *RAD51C* (2), and *RAD51D* (1). The total number of pathogenic variants is 25 because 1 patient had 2 pathogenic variants.

Informed choices?

- Almost 60% of women who had CPM did not understand its lack of survival benefit
 - 35% of women at average risk, and 48% of women at high risk correctly understood

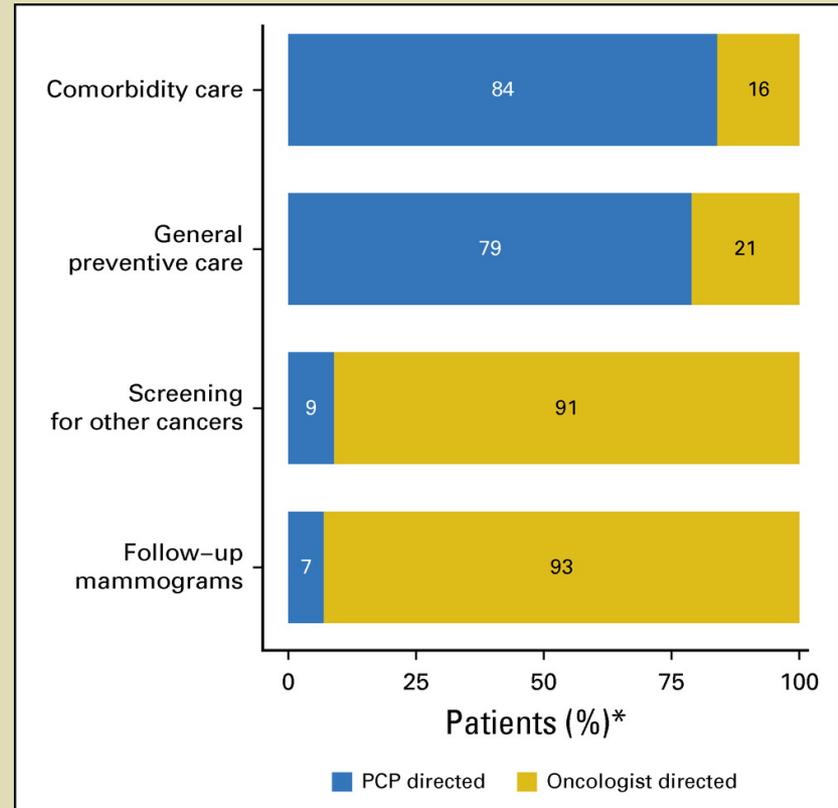
Values and Preferences

- Patients have distinct values around attributes of treatment that matter when making treatment decisions



Preferences for provider roles

- Patients have distinct preferences for provider roles during cancer care



So....

- We can do better with regard to 2 components of patient centered care that define a high quality decision
 - Still need to ensure people are informed
 - Preferences and values need to be addressed and considered across multiple decision points, including treatment attributes and provider roles

How can we help patients?

- Interventions for improving decision making for patients



- Individualizing decision making: An online interactive decision tool to help women make decisions about their breast cancer care (P01 Project #3)
- N=22 surgical practices in 4 states
- 540 patients enrolled



Aim and Hypotheses

- ▶ To evaluate the impact of an online interactive decision tool on **decision making for locoregional AND systemic treatment** among newly diagnosed patients with early stage breast cancer
 - ▶ Patients who view the online interactive decision tool (intervention) have a higher rate of high quality decisions (informed and values concordant treatment) for locoregional and systemic treatment than those who view online standard information (control).

Summary of the protocol

Practice

- Patient identified by practice as eligible (early stage breast cancer, considering mastectomy or lumpectomy with radiation)
- Someone from practice gives patient intro packet (contains introductory letter and login information sheet)

Patient

- Patient logs in, completes consent and is randomized to ICanDecide intervention (interactive website) vs. ICanDecide control (static website)
- Patient views locoregional modules
- 2 weeks later: Patient is notified that systemic modules are available

Eval

- 4-5 weeks after enrollment: first follow up survey (primary outcome, locoregional treatment)
- 9 months after enrollment: second follow up survey (secondary outcome, systemic treatment)

Current patient interface



Knowledge building

Fact 1 Eight Important Facts About Breast Cancer Treatment

Key Fact 2: Recurrence

- Distant recurrence:** The chance of your cancer coming back somewhere else in the body is the same, no matter which treatment you choose.
- Local or regional recurrence:** The chance of your cancer coming back in the area of the surgery (breast, mastectomy scar or lymph glands) is low, no matter which treatment you choose.

• • • What is recurrence?

Cancer "recurrence" means the cancer returns, usually within 5 to 6 years after surgery. It is not the same as getting a new cancer, which is very uncommon. After 6 to 8 years, the chance of breast cancer coming back is about the same as the chance of getting a new cancer.

Recurrence can happen in several ways:

- Local recurrence:** The cancer returns to the same, or "primary," tumor location. This could be in the same breast or in the chest wall.
- Regional recurrence:** The cancer comes back in the lymph nodes near the breast, such as the axilla or armpit area.
- Distant recurrence, or metastasis:** The cancer comes back in a different spot. This means cancer has spread somewhere else in your body. The most common places are the liver, lungs, or bones.

• • • What causes recurrence?

Recurrence happens when cancer cells have broken loose from the tumor before surgery. These cells may be inactive for a long time. Usually they are too small to be found until they start growing again. It is not always clear what causes the cells to begin growing again. When drug therapy (like chemotherapy or hormonal therapy) is recommended after surgery, it is to try and kill any cells that may have already broken loose from the cancer.

Sometimes a new tumor grows in the same breast or the other breast. **This is not recurrence.** It is a new, separate cancer.

Tailored Patient Activation

I must have asked the surgeon about 8 million questions. But she was great about answering all of them.



I didn't know what I wanted to do. I'd say I wanted one thing, but then quickly talk myself out of it. I felt like I had to keep asking questions.

One of the things I asked about was which treatment would be easier for me. I wanted to treat the cancer in the easiest way so I could move on and get back to my life.

But the doctor pointed out that it's not black and white to say one treatment is easier or lets you move on faster. What's easy to one person may seem hard to another. She asked me more questions about what I really wanted my next 6 months or so to be like. And she gave me a lot to think about.

Even though I worried I was annoying her, the surgeon actually told me she was *glad* I asked so many questions. She said she finds it comforting when patients are careful. She gets nervous when people decide about their treatment very quickly, without taking enough time to think things through. She even told me I could think about my options for awhile—even a few weeks—before deciding.

I'll probably even go back and see her again. I have more questions. I've been reading a lot online and I want to make sure I really understand it. I also know not everything I read online is correct, so talking to my surgeon will help me make sure I have the most accurate information.

Part of me wants the surgeon to just pick the best treatment. But I also want to make sure she knows what's important to me. I need to ask a few more questions to be sure that I'm comfortable with her recommendation.

Values assessment & feedback

• • • Here's how each treatment matches your answers.

Why?

Most important:

- You accept a higher chance of complications
- You prefer a shorter recovery time

Less important:

- You accept that you may need radiation
- You accept the need for more surgery to remove cancer

Compare

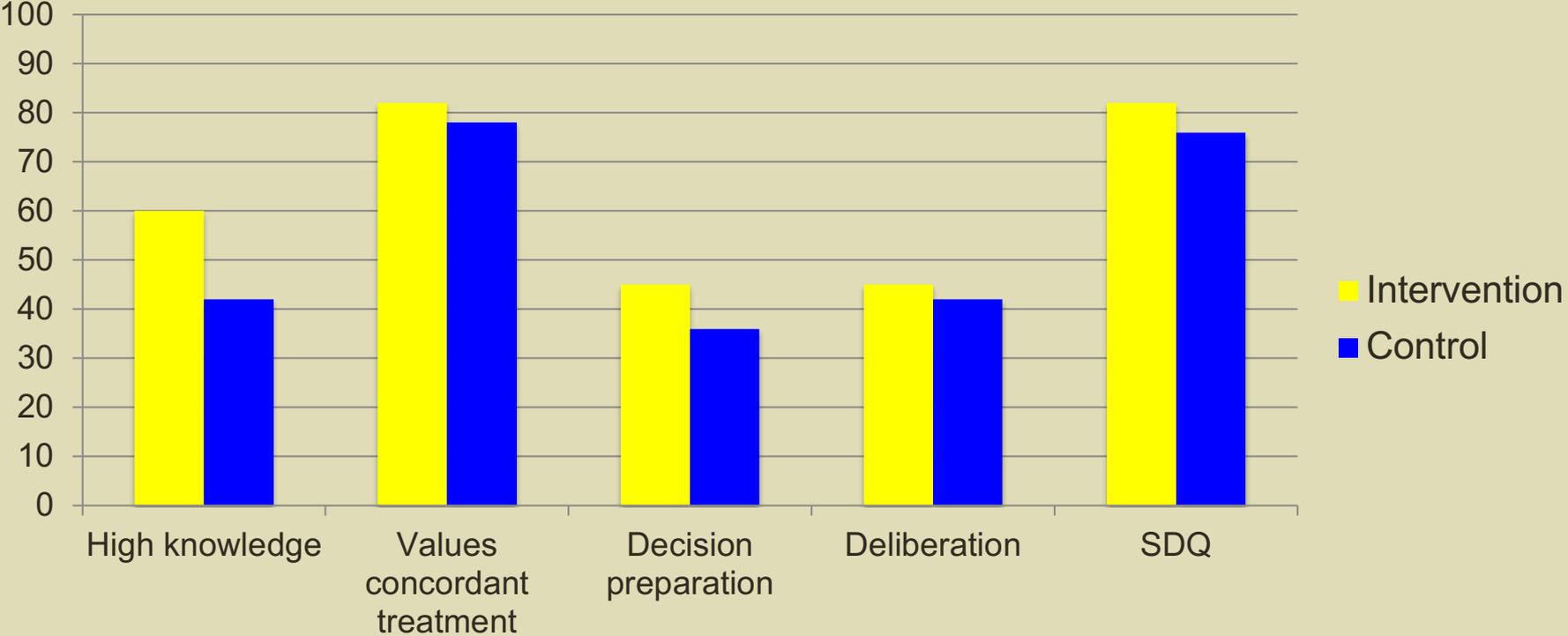
Continue

Click any colored section to learn more

Treatment	Most important (Green)	Less important (Blue)
Lumpectomy	High	High
Mastectomy	Medium	Medium
Mastectomy with Reconstruction	Low	High

Primary outcomes analysis

Locoregional Treatment



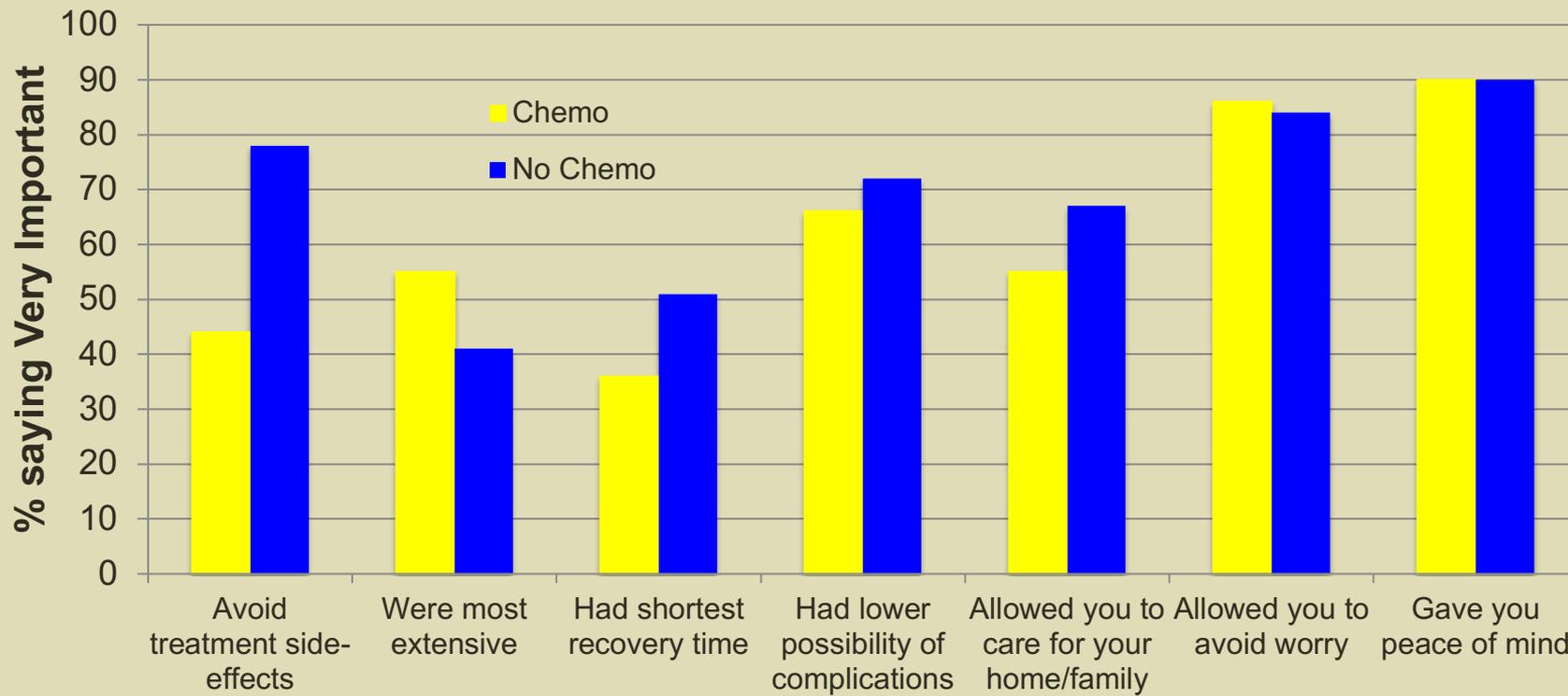
**P<0.001, *P<0.01

Systemic outcomes by study group

	Intervention	Control
Knowledge about systemic treatment	2.9 (1.1)	2.4 (1.2)**
SDQ for systemic treatment	4.6 (0.7)	4.5 (1.0)

**P<0.01

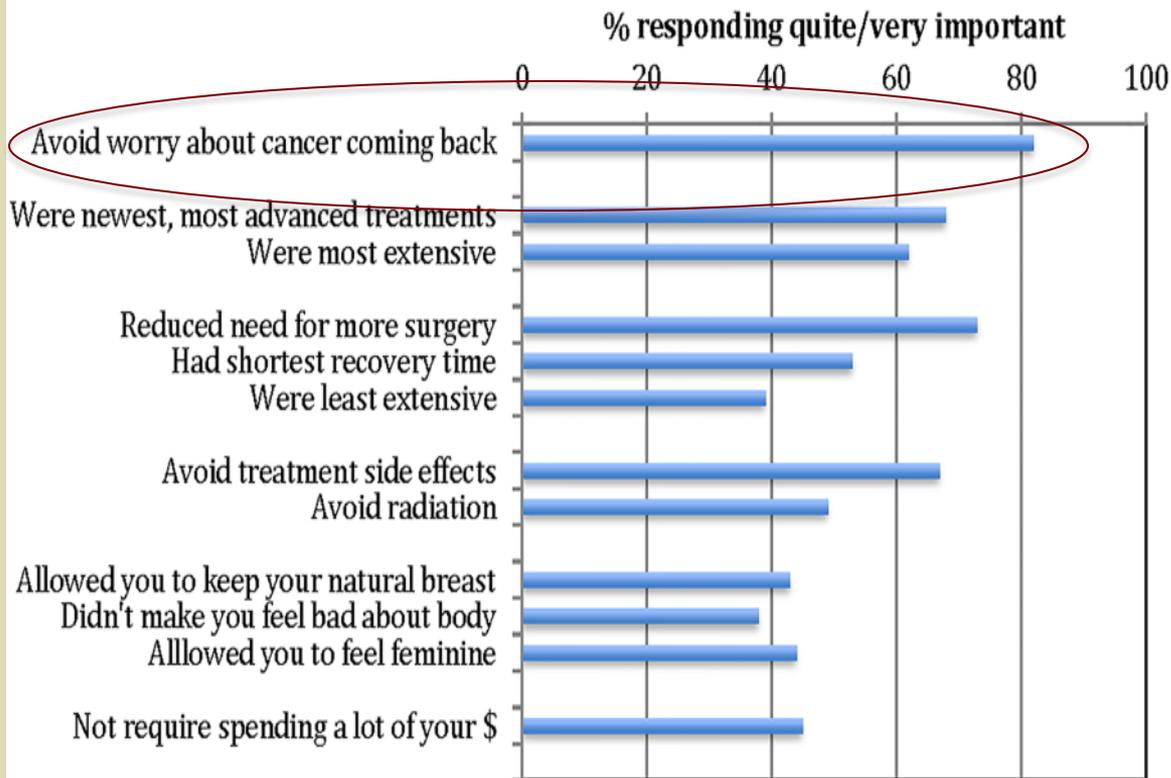
Values and Chemotherapy Receipt



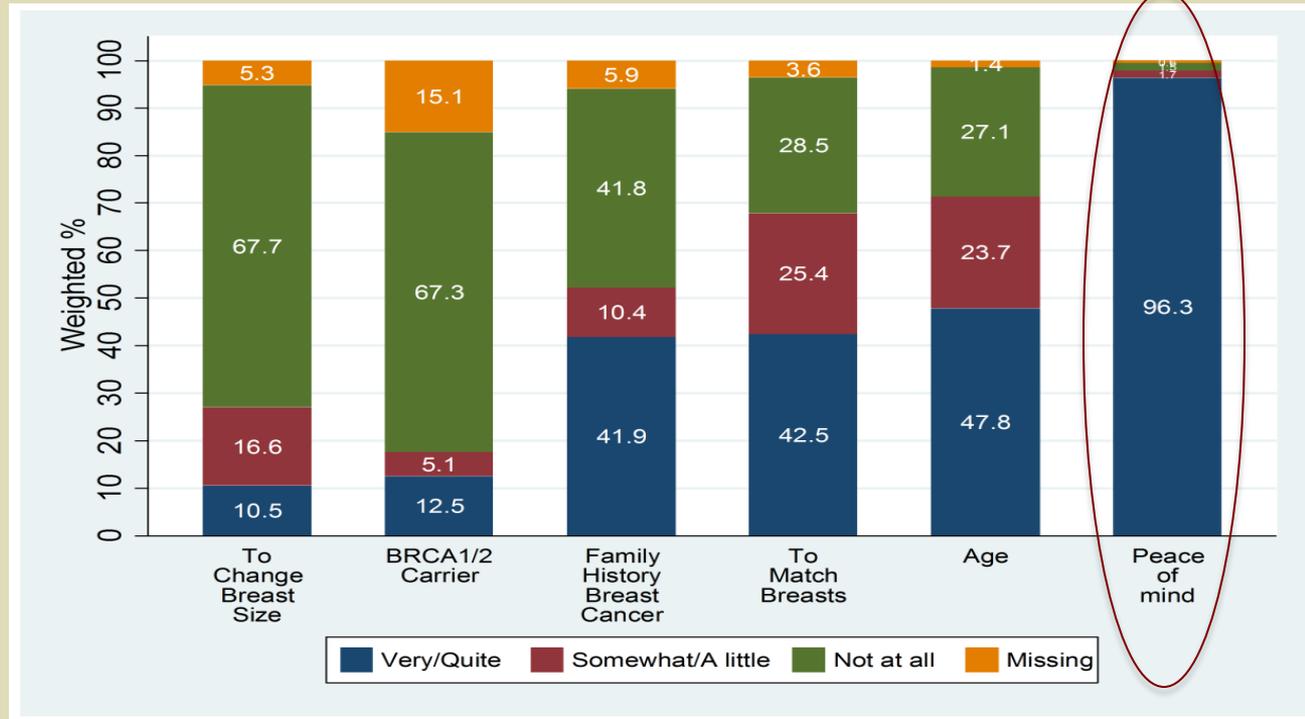
Summary

- A tailored, interactive treatment decision tool shows promise for improving decision quality
- Other factors still need to be considered to improve patient centered care
 - Emotion and worry
 - Role of others
 - Need to engage clinicians

When making your treatment decision, how important was it that the treatment(s).....

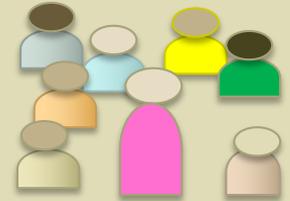


Motivations for CPM



Role of others

- Half of breast cancer patients report having 3 or more decision support persons (DSP)



- Over 80% say that the input of spouse, friends and family is “very important” in their treatment decision making

DSPs contribute to patient deliberation

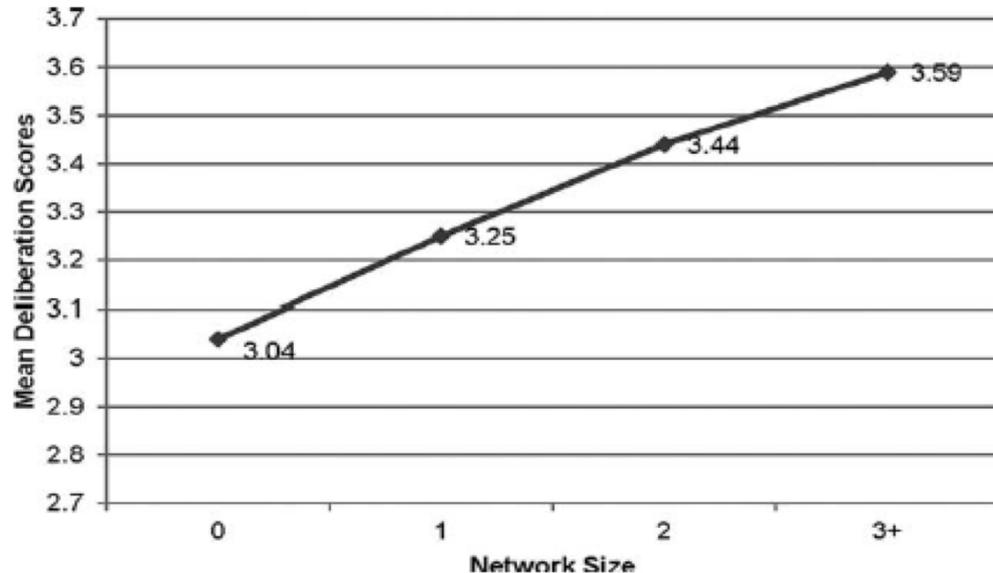
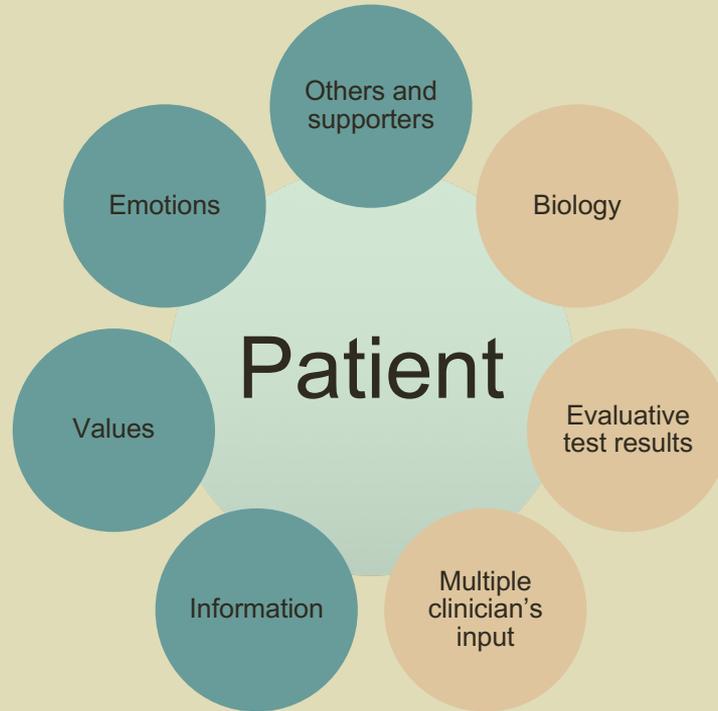


Figure 2. Adjusted mean treatment deliberation scores are illustrated by network size ($P < .001$). Analyses were adjusted for age; race; insurance status; education; partner status; comorbidity; Surveillance, Epidemiology, and End Results stage; and surgical treatment.

Many influential factors



Take Home



- Achieving patient centered care is becoming more challenging and more important
 - Multiple influences both clinical & personal
- Underscores the need for tools that can personalize decisions for patients, but can allow for patient-physician discussion

Next Steps

- Enhancements to address role of emotion and worry
 - Module to incorporate support persons
 - More focus on interpreting results of evaluative testing
- 
- Feedback to clinician to support shared decision making
 - Integrate into clinical delivery systems

EAB



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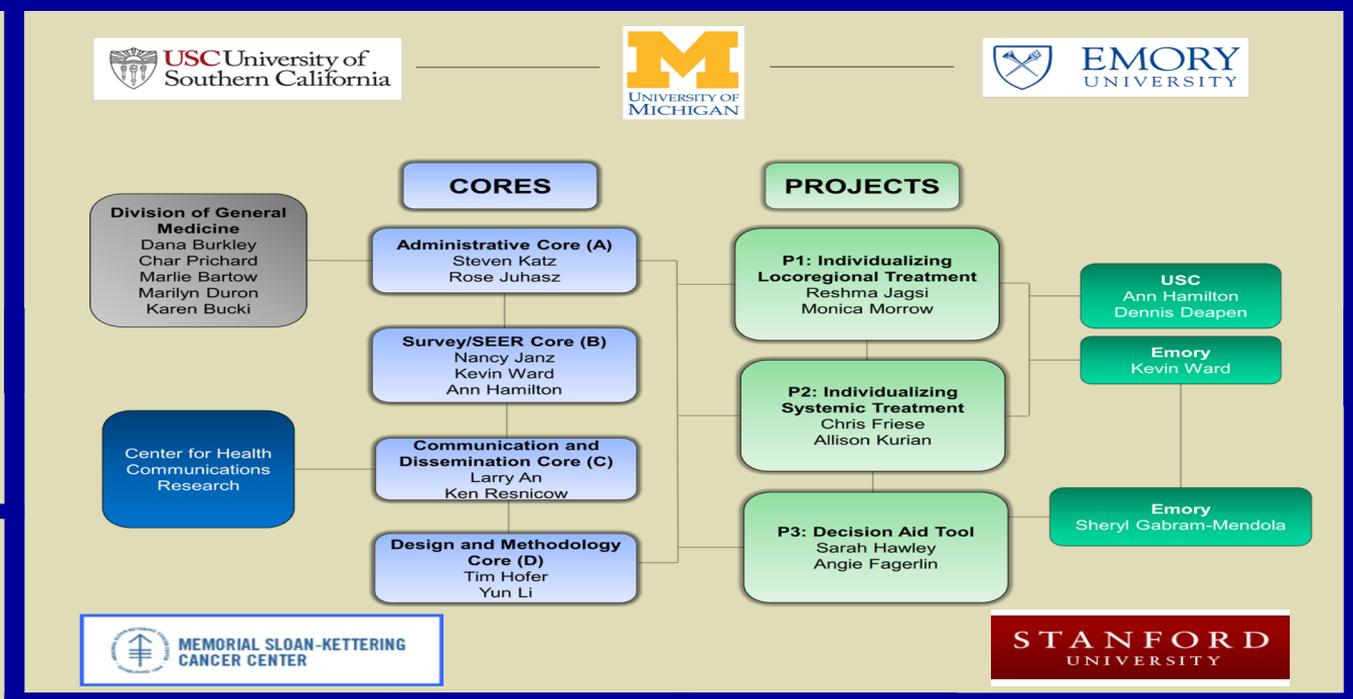


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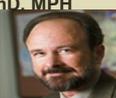
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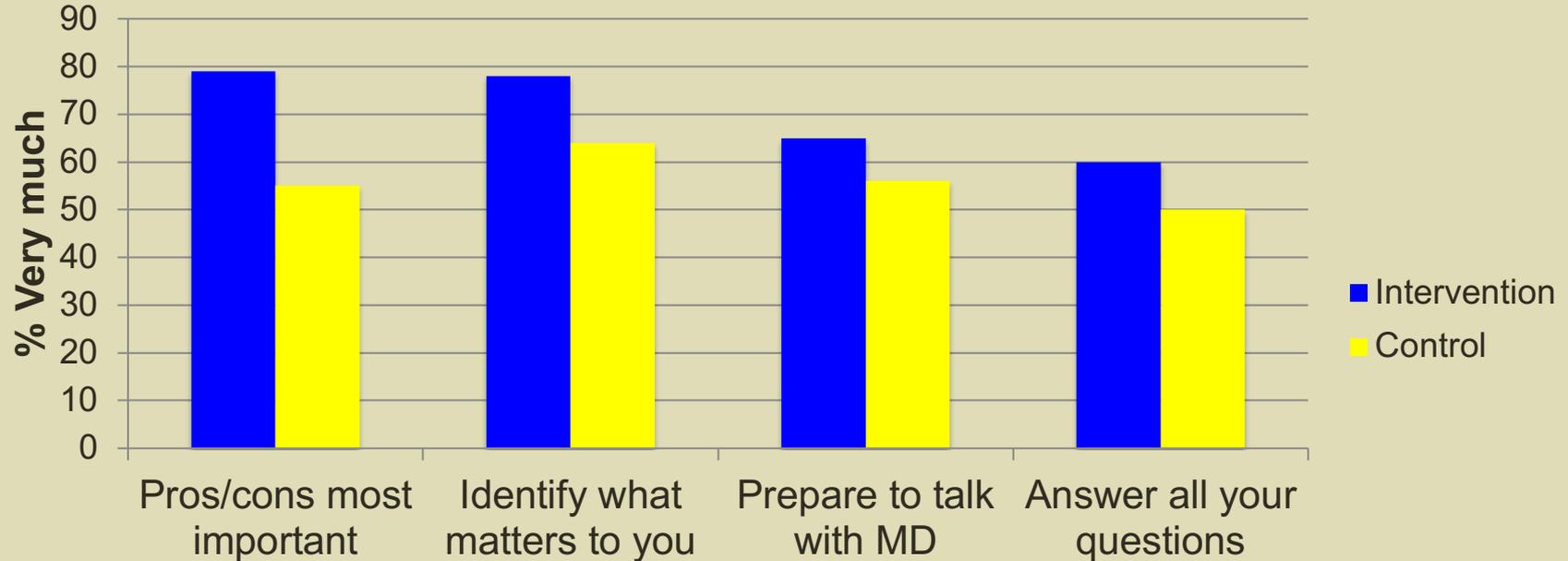
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Appraisal



Did the website help you by...



Worry among survivors and partners

