Decision Making and Communication about Contralateral Prophylactic Mastectomy

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Collaborators

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Growing use of contralateral prophylactic mastectomy (CPM)

- 2% in 1998 to 12% in 2011 (33% younger)
- Recommended for familial cases
- Most patients who have CPM have non-familial cancer.
- More common in younger, white, educated, higher-income, or privately-insured women
- Associated with MRI, academic site

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Yao K, Ann Surg Onc 2010
Tuttle T, JCO 2007
Yao K, JACS 2014
Hawley S, JAMA Surg 2014

Why do patients have CPM?

- Prevent future cancer
- Reduce worry or have “peace of mind”
- Avoid mammograms
- Improve appearance

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Rosenberg S, Ann Int Med 2013
Soran A, Am J Clin Onc 2013
Unukovych D, Eur J Cancer 2012
Frost M, Ann Surg Onc 2011

What is the evidence?

- Benefits:
  - Reduces risk of contralateral breast cancer
  - No or minimal impact on survival
  - ? impact on patient-reported outcomes
- Harms:
  - More unplanned surgery
  - Adverse effects on appearance, femininity, sexuality, self-esteem
  - Higher complication risk (especially with reconstruction)
  - Higher short-term costs

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Portschy P, JNCI 2014
Kurian A, JAMA 2014
Pesce C, Ann Surg Onc 2014
Silva A, Ann Surg Onc 2015
Hwang E, JCO 2016

The quality of decisions is not known

- Good decision: informed, concordant with preferences, accurate expectations
  - Informed: knowledge about cosmesis, sensation, recovery, complications, reconstruction not measured
  - Preferences: measured after treatment; concordance not assessed; preferences about reconstruction not elicited
  - Expectations: no study has measured accuracy of expectations
- Prior studies: retrospective, cross-sectional, homogeneous, single-site, lack control group (unilateral mastectomy, BCT)

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Rosenberg S, Ann Int Med 2013
Frost M, Ann Surg Onc 2011
Abbott Ann Surg Onc 2011
Montgomery L, Ann Surg Onc 1999

What are patients and providers saying about CPM?

- Patients appear to initiate conversations about CPM
- Providers may feel pressure to agree
- Actual conversations?

Covelli A, Ann Surg Onc 2014
Balch C, Ann Surg Onc 2009
Musiello T Anz J Surg 2013
Covelli A, Ann Surg Onc 2014

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Specific aims

1. Describe how patient knowledge, preferences, and predictions about future well-being shape decisions about CPM.
2. Evaluate patient-provider communication about CPM for informed decision making, discussion of benefits/harms, provider influence, and patient activation.
3. Compare patient predictions about future well-being to actual outcomes at 12 months.

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Study design

- Prospective cohort study
- Population: Younger (<60) women with unilateral, non-familial DCIS or Stage I-III invasive breast cancer
- Enrollment: prior to first surgical visit
- Data collection:
  - Brief pre-visit survey
  - Audio recording of visit
  - Post-visit survey
  - 12 month survey

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Goals for recruitment through the Alliance

- Large, diverse sample of providers
- Generalizability to community and academic practices
- Generalizability by geography, race/ethnicity, urban/rural settings
- Possible:
  - Large-scale rapid enrollment could allow for longer-term follow-up.
  - Larger sample could allow evaluation of outcomes, in addition to decision making.

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Feasibility

- Enrollment and assessment of decision making prior to surgery:
  - Lee reconstruction cohort at UNC: 83% participation rate, 88% retention at 12 months
  - Hawley decision aid RCT at 20 practices
- Audio recording:
  - Prostate cancer study: 1028 patients at 4 sites
  - CPM pilot study of audio recording:
    - UNC: 3 surgeons; 8 of 14 patients consented to recording
    - MGH: 3 surgeons; 13 of 15 patients consented to recording
    - Michigan: 2 surgeons; 4 of 5 consented to recording – still enrolling

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Conclusion

- Questions from Audience
- Answers from Presenter

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