## Disclosures

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<th>Company</th>
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“What do other people do?”

• Not everyone follows the same path in BRCA decisions:
  • 20% or less choose bilateral mastectomy in 1st 1-3 years after BRCA testing (in US)
  • ~50% choose bilateral mastectomy when BRCA testing done at cancer diagnosis

• Balance of benefits & drawbacks and meaning of decisions vary from person to person

• Rate for RRBM may be increasing over time

Schwartz et al., 2005
Lokich et al., 2014
Cortesi et al., 2014
Flippo-Morton et al., 2016
“Just tell me what to do”

• Can foreclose cognitive and emotional processing

• Can contribute to process and outcome regret

• Can delay or inhibit development of coping strategies that affect adjustment

• Can disrupt rapport between you and your doctor
One BRCA mutation, many life paths

Minimal family history

• Uncle on father’s side died of pancreatic cancer at age 53

• No other cancer in three generations

• A’s husband finds lump on her breast

• A offered genetic testing on the spot when biopsy is positive

Extensive family history

• Grandmother & 2 aunts on mother’s side died of breast cancer, all in their 30’s & 40’s

• Mother had breast cancer when B was 12; B very involved in taking care of mother & siblings

• B seeks genetic testing to learn about her own risk
The decision landscape
Choosing to test is just the first decision...

Screening vs. surgery?

What do I tell the kids?

Should I ask Dad to get tested?

TRAM flap or implants?

HRT?

Should I try to get pregnant?

Do we talk about this on the 1st date? The 5th?

Nipple sparing?

Tamoxifen?
Decision features

• “Avalanche” – people may not realize how many decisions will be presented to them when they undergo testing

• Risk information is highly technical and probabilistic

• Individual choices directly and indirectly affect other relatives
Randomness

• Genetic risk is random – science cannot explain who gets it and who doesn’t

• Goes against beliefs about order and fairness
When you’re the one...
Tolerating uncertainty

• State of uncertainty before decision is made can be frustrating and uncomfortable

• Need to be able to tolerate discomfort until decision process is fully explored

• Requires trust that if process is completed, decision will “gel” or “glide into place.”

• “Pivotal moment” when decision arrives

McQuirter et al 2010
Time pressure

• Anxiety increases sensation that there is no time to think

• Preoccupation with time pressure may be avoidance of painful feelings
Battle mind

• Common coping mechanism for getting through surgery or treatment

• “Get it done” mentality regardless of how you feel or the long-term cost
Focus on self

• Decision requires that you know your own priorities and feelings

• Self-focus may be more difficult for:
  • Those socialized to focus on needs of others
  • Those in caretaking occupations (e.g., nurses, teachers)
  • Those in rescue/protective occupations (e.g., military, police, firefighters)
  • Those who had significant caretaking responsibilities in childhood (ill or missing parent, eldest child)
Isolation

• Hereditary risk has features that can trigger feelings of isolation
  • “Science fiction” quality of choices
  • Available choices seem drastic
  • Alphabet soup
  • Reactions from others
    • Scared/don’t know what to say
    • Haven’t had to make big decisions
Imperfect choices

• Acceptance that none of the alternatives are ideal

• Limits of current knowledge

• Historical perspective – future advances may make current choices look primitive
The decision process
Decision Process

• Cognitive level: Collecting all relevant facts and understanding them

• Emotional level: Dealing with feelings about the decision and how it fits into other parts of life (family, life plans, stressors, mental health history)

• Action level: Having knowledge, coping strategies & support to carry out decision and live well with the consequences

Jeffers et al 2014
Howard et al 2010
Regret after surgery

• Most studies show that majority of patients do not regret risk-reducing surgery decisions

• Factors associated with regret:
  • Dissatisfaction with preparatory information
  • Depressed mood before surgery
  • Pursuing surgery due to physician recommendation, not personal motivation

Gahm et al, Breast, 2010
Types of regret

• Outcome regret: regretting how things turned out as a result of a decision

• Process regret: regretting the steps one did or did not take to make a decision

• Minimizing process regret can reduce the probability of outcome regret (but does not guarantee satisfaction)

Connolly & Reb, Health Psych, 2005
Information hygiene

What is the one next thing you need to know?
Stress pile-up

• Negative events, even if unrelated to genetic testing or cancer, make it more likely that testing, surgery, diagnosis and/or treatment will be distressing.

• Negative events have this impact regardless of whether they happen before or after.
  • Traumatic car accident 10 years ago
  • Spouse laid off six months after surgery
Self and Others
Partner involvement

• Body ownership

• Shared physical experience

• Childbearing plans

• Helplessness
The Mensch Test

“Of course I’ll love you no matter what you decide.”

- May be hard to believe even if true
- Does not allow room for doubts or sadness
- Safe space and support essential for communication
Faultlines

- Decision may expose weaknesses in relationship
- Decision may reveal that habitual coping strategies are inadequate

Yalom, *Existential Psychotherapy*, 1980
Physician Recommendation

• Physician recommendation is a powerful determinant of health decisions and behaviors

• Patients who choose surgery because their physician told them to may be more likely to experience regret

• Physician may have strong feeling or opinion that differs from patient
Social support

• Closest supports may be affected by your decision
• Find at least one neutral person who can listen without judging
• Those who do not confide at risk for prolonged distress
“Don’t go to the hardware store looking for oranges”

Family members will likely not change long-term patterns because you need them more
Existential Concerns
Limitation

• Heidigger: Death is the impossibility of further possibility

• Decision closes off alternate possibilities

• Paradoxical reminder of mortality, stimulating anxiety

Yalom, *Existential Psychotherapy*, 1980
Responsibility

• Confronting human condition of responsibility for own actions

• Acute feeling of aloneness

• May be more difficult to tolerate for those who are grieving, or feeling isolated by risk status
Distance

• Making a decision may put distance between others who are not ready to take a stand

• Acknowledgment of mortality may distance one from peers who are not ready to accept limits of life
Exposure

• Making a decision may trigger memories or regrets about other decisions that have gone unmade

• Undermines old stories of blame and passivity
Will

• Decision may expose that person was squelched as a child

• May trigger painful memories and realizations of lack of support or encouragement
Resolution
Antidote

• Antidote to existential weight of decision-making is meaning

• Understanding how decision
  • Fulfills one’s goals
  • Connects one to others
  • Gives sense of purpose
“Can you say in a sentence what your decision with do for you?”
Red Flags

• “Just tell me what to do”
• Internet overload
• Preoccupation with small differences
• Numbness/indifference
• Excessive crying/anxiety
• No one to confide in
Hallmarks of good decision

• Knowledgeable
• Informed but not overloaded
• Realistic expectations
• Clear goals
• Adequate support
The take home message

• How you make a decision is as important as what you decide
• Good decision process reduces risk of regret later
• Normal to have some anxiety even after decision is made
• Decision process provides opportunity for growth
• Decision process puts you on good footing for coping with future stress and uncertainty