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# Pros and Cons from the Patient Perspective in the Three Phases

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# Presentation Objectives

- Describe patients’ perspective on over testing
- The fears of knowing and not knowing
- Patient perspective and experience of screening, staging and surveillance – in the real world
- Fear of missed diagnosis leading to over screening
- Fear of initial diagnosis and treatment side effects
- Fear of recurrence and how it affects post cancer care and surveillance
- Coping with the fears of all aspects of cancer – resources and personal advice
- A personal experience

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# What is patient perspective?

*It is not data, it is not risk calculations, or recurrent scores. It is "what if it happens to me!"*

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# Patient Perspective Screening

- Fear of screening – basic fear of having cancer
- Afraid to be screened if they believe they already have cancer - “Ignorance is bliss”
- Elderly – Misperception that that I will die from my cancer if it is not treated, do not consider other conditions nor age
- Screenings will ensure detection at a “curable stage”
- Risk their progeny/family could be at risk (Genetic testing?)

# Fear of Initial Diagnosis

- If a symptom prompts a diagnostic test:
  - Patient & family are anxious until results are known
  - Delays are terrifying!
  - Want results immediately!
  - Want to know if it is curable?
  - If surgery not scheduled ..they want to know why?
    - Want the cancer removed now!
  - Will I need chemo or radiation?
  - Can I still work?
  - How is it going to affect my family?

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# Fear of Adverse Side Effects

- Will I lose my hair! (men & women)
- Will my spouse love me with a colostomy or disfiguring surgery (Mastectomy)?
- Will intimacy be possible?
- Sexual concerns are the most common unstated problem
- How long will treatment take?
- Will I lose my job?

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# Patient Perspective
# Staging Tests

- Often do not understand why staging is necessary?
- Don’t understand the delay in starting treatment?
- Lack of understanding of timeline and the delays in obtaining results… (genomic tests ~weeks)
- Afraid that they might find more cancer?
- Lack of understanding of limitations of staging and that more cancer could be missed
- Often believe most advanced technology is the “necessary test”- MRI or PET

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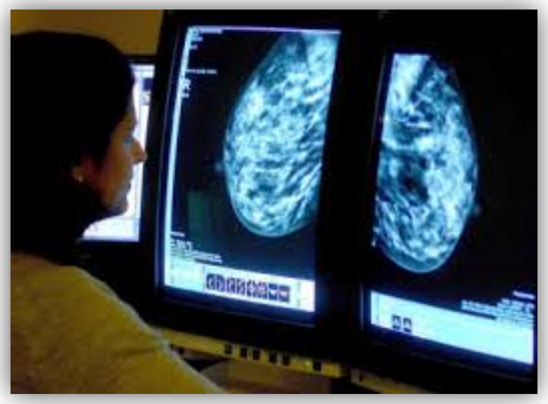
# Patient Perspective Surveillance



- Peace of mind!
- Requesting non-validated testing looking for cancer
- Want scans more frequently
- Believe earlier detection makes the recurrence more treatable
- Constant anxiety over the cancer coming back
- Poor understanding of surveillance testing and the implications of "abnormal" lab values and "residual" findings on imaging

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# Screening - Guidelines

- Patients poorly understand the concept of guidelines
- What is the risk/benefit of screening
- Easy to understand the benefit… the risk is much more complicated
- Weighing risk is very personal and subjective

# Screening Outside of Guidelines

- We all know a man under 50 with prostate cancer or colon cancer
- We all know a woman under 40 with breast cancer
- I don’t want to hear from my doctor “it is rare for someone under 40 to get breast cancer.” I could be that one!

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# Screening Outside of Guidelines

- If I am worried about cancer I don't care about guidelines, I just want to be screened
- Patients don't worry about radiation exposure…feel imaging is safe
- Some patients over-worry about radiation exposure…feel imaging is dangerous
- Many people feel screening guidelines are there to save money

# My Perspective

- I am now biased towards over-testing with my own experience
- I want my female relatives screened even though guidelines do not recommend before 40 for my relatives

# Patient Perspective
# Watchful Waiting

- Most patients want to get rid of it - period
- They don’t want cancer in their body regardless of their age
- They want “a cure”
- Afraid cancer is going to get worse and harder to treat
- Don’t understand watchful waiting?
- Difficulty understanding competing co-morbidities
- They want to do “something” action

# Patient Perspective of Fear of Missed Diagnosis

- Fear the diagnosis will be too late if interval between scans are too long “per guidelines”
- Patients panic when told they don’t need to come back for a year

# Patient Perspective
# Financial Concerns

- Patients don't believe we care about their costs
- Most patients don't understand their insurance
- Patients worry that treatment will be withheld if they don't pay co-pays/bills
- Worry about paying for prescriptions and "tests"
- Balance food and medical bills
- Offer financial counseling to all patients up front, everyone will end up having financial issues

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# Disparities

- Non-Caucasians are afraid of research because of past history
- LGBT-often worry they will not be treated with the same standard of care
- Elderly worry their symptoms will be attributed to age
- Elderly don't understand benefits of palliative care
- Unfunded worry you are stopping surveillance because they can't pay
- Non English speaking patients worried they are not receiving the "best" treatment

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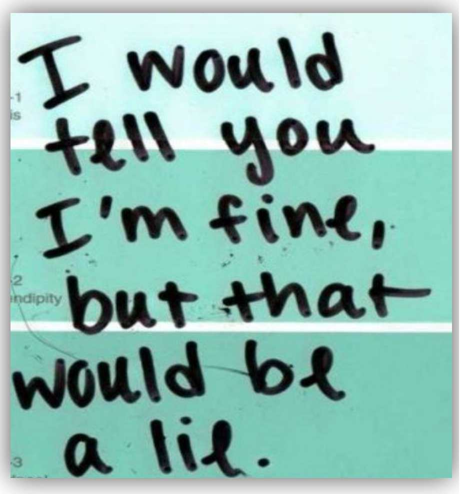
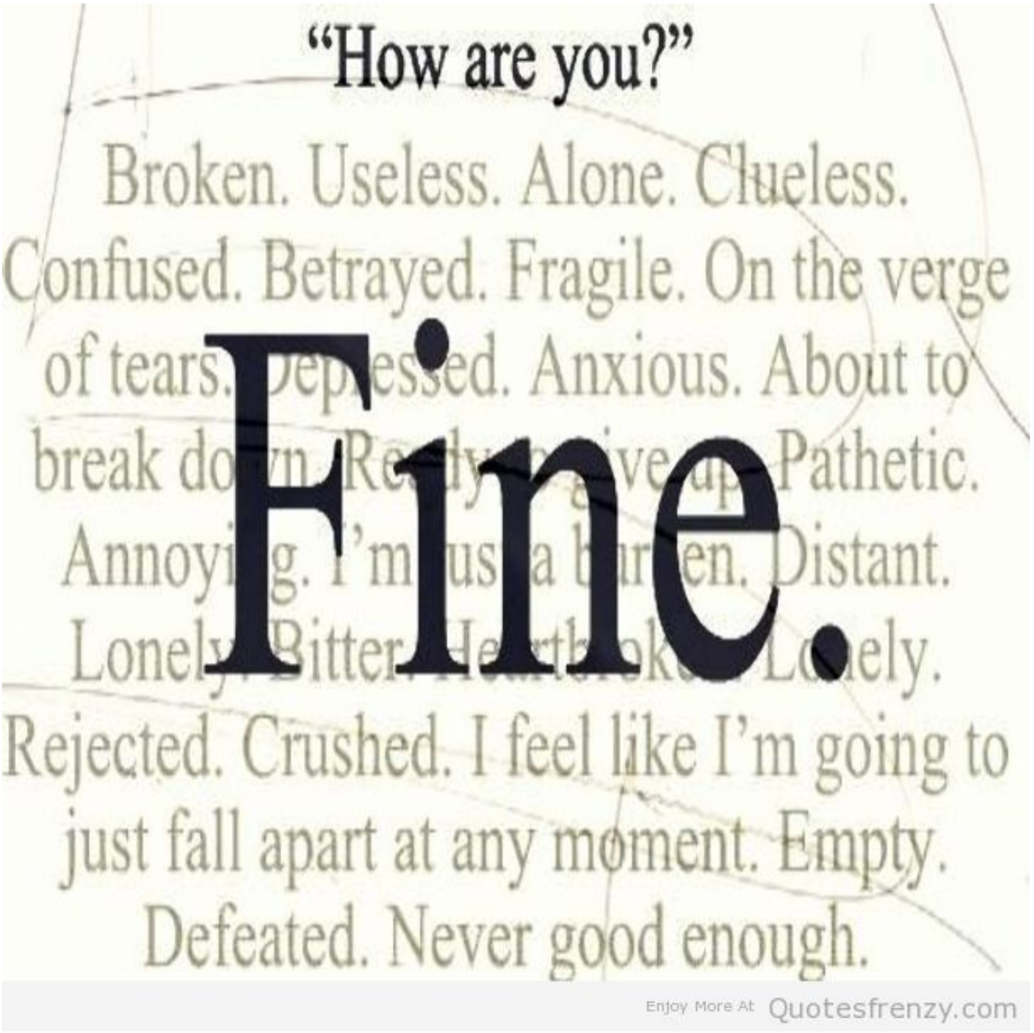
# Personal Advice



I would tell you I'm fine, but that would be a lie.

- Build my trust
- Assess my understanding and knowledge
- Listen to my fears
- Repetition, tell me again, again, and again
- Build my knowledge
- Speak to me in my language…don't use % give me something I can understand and relate to

# *What do patients mean when they answer “fine” ?*



“How are you?”

Broken. Useless. Alone. Clueless. Confused. Betrayed. Fragile. On the verge of tears. Depressed. Anxious. About to break down. Ready to give up. Pathetic. Annoying. I’m just a burden. Distant. Lonely. Bitter. Heartbroken. Lonely. Rejected. Crushed. I feel like I’m going to just fall apart at any moment. Empty. Defeated. Never good enough.

Fine.

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When patients say “I’ m fine”…

You might say

*“Tell me how you really feel…*
*I care”*

People don't always need advice. Sometimes all they need is a hand to hold, ear to listen & a heart to understand.

# Questions

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# Thank You

AnneMarie Ciccarella, National Patient Advocate & Survivor 2006

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