Pros and Cons from the Patient Perspective in the Three Phases

Wanda M. Burdette, RN, OCN, CCRP
Spartanburg Regional Medical Center
SCOR NCORP
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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
What is patient perspective?

It is not data, it is not risk calculations, or recurrent scores. It is “what if it happens to me!”
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?
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?
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
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
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!
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
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
Personal Advice

- 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”?
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
Thank You

AnneMarie Ciccarella, National Patient Advocate & Survivor 2006

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