Role of Advocacy in Preoperative Trials

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Role of the Advocate

- Provide the patient perspective
- Support the “good” science
- Translate the science for the patient
- Support patients in their decision-making
- Influence policy
Advocate or patient… is there a difference?

<table>
<thead>
<tr>
<th>Patient</th>
<th>Advocate</th>
</tr>
</thead>
<tbody>
<tr>
<td>• May know a little or a lot about their disease</td>
<td>• Has more in depth knowledge about disease</td>
</tr>
<tr>
<td>• Focus is on self, family</td>
<td>• Focus is on the healthcare system/research</td>
</tr>
<tr>
<td>• Main concern is treatment</td>
<td>• Main concern is influencing research and healthcare delivery</td>
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<tr>
<td>• Emotions play significant role in decision making</td>
<td>• Emotions are channeled into working for larger community</td>
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The Patient Perspective

- It is not about the science
- It is about the patient
- The needs and concerns of the patient in making an informed decision about preoperative therapy
What Patients Think and Hear

- Get it OUT!
- Cancer Cells even in a small tumor can migrate to other locations through the blood stream
- “Aunt Minnie didn’t have preoperative therapy”
<table>
<thead>
<tr>
<th>Options – lots of</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>✓ Doctors are able to offer patient options</td>
<td>✓ Patients want the “best” treatment</td>
</tr>
<tr>
<td>✓ Doctors are fascinated by the science</td>
<td>✓ Patients are frightened by the word cancer</td>
</tr>
<tr>
<td>✓ Doctors don’t have a lot of time</td>
<td>✓ Patients need time to absorb what is happening</td>
</tr>
<tr>
<td>✓ Doctors think they have explained EVERYTHING</td>
<td>✓ Patients say they understand but…..</td>
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</tbody>
</table>
The Words Don’t Help

Neo-adjuvant

Pre-operative

Biomarkers

Breast Conservation

Gene Profile

Node Dissection

Sentinel node biopsies

Imaging Choices

Core Biopsies

Tumor Markers
This is a Life Decision

- Not just a medical decision
- Are there extra costs – even those insured may have a 20 or 30% co-pay?
- Are there extra treatments – pain and suffering?
- Will preoperative treatment compromise my functioning or future treatment choices?
- Will more time be required?
  - Away from work
  - Away from family
What Educational Tools are Out There?

- Tissue Research
  - NCI Booklet
  - RAN Booklet
  - Success story of advocates and NCI working together
  - Outcome
    - more information for patients
Patient Education Materials
Advocate Questions

- What does this add to the treatment?
- Longer life, more certainty?
- What does this add to the science?
- Is this a proven therapy?
- Is this ready for prime time?
- How is it being used in the community?
Is This Replicable in the Community?

- Are patients at academic medical centers the same as those in the community?
- ECOG found average age of women in their breast cancer trials was 51
- The SEER data shows the average age of breast cancer patients is 65
- Patients at academic medical centers who enter trials are also white, better educated and higher socio-economic status
Research and Advocate Interests

Example – ACOSOG Z1031 (Alzheimer's Preoperative Study)

- Advocate Interest
  - What AI is best?
  - What patient population?
  - How to educate patients?

- Research Interest
  - All of the above and how to combine AI and chemo in preoperative therapy?
What You are Doing is Important!

• Advocates
  – Can inform the process
  – Need Information
  – Want the opportunity to ask questions
  – Will provide patient with information
  – Get the word out!!!!