Importance of Patient Advocates in Teams

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What is the role of the advocate in the advancement of Teams in Cancer Care

- Researchers want to advance the science
- Patients want access to better treatments and care
- Advocates are the bridge
  - Reflecting the patient viewpoint
  - Their needs and concerns
  - Questions and unique life situations

“Capturing and clearly addressing the concerns of most people is generally out of reach of those of us who speak and think only in medicalese; the advocates bridge that gap for us. The sustained commitment of the advocates to help others with cancer, often despite their own ongoing battles with cancer, is both humbling and motivating.”

NCI-ASCO Teams
Advocate involvement can add value

- Advocates can bring the patient perspective to the following topics
  - Purpose and composition of the team
  - Role of the patient
  - Communication
  - Goals of the patient
  - Managing symptoms
  - Future research
Cancer Care is Complex

• Especially to a newly diagnosed individual
  – New terms, e.g., biopsy, biomarker tests, CT scans, MRIs

  – New health care providers – surgeons, oncologists, radiologists, pathologists, genetic counselors

  – Treatments right out of a horror movie – you can be slashed, burned or poisoned
How can a team approach simplify the patient experience?

- Reduce morbidity and mortality
- Coordinate care for the patient
- Improve patient safety
- Enhance pain control
- Improve adherence to oral medication
- Increase patient satisfaction with care
Goals

• The team approach starts with agreed upon goals. Does the care team includes the goals of the patient?
  – Do we ask the patient what their goal is?
  – Do we ask them what meeting that goal would look like?
  – Do we recognize a patient’s goals may change over time?

• A patient’s choice not to be screened or treated acknowledges the reality of different patient preferences in goal setting
Composition of the care team

Is the patient a member of the team?

Is the caregiver a member of the team?

How is team explained to the patient and caregiver?
## Coordination of Care

<table>
<thead>
<tr>
<th>Clinicians work TOGETHER</th>
<th>Clinicians work INDIVIDUALLY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Better patient outcomes</td>
<td>Patient is confused about who to tell what…Resulting in lack of adherence to treatment plans</td>
</tr>
<tr>
<td>Comorbidities and side effects quickly managed</td>
<td>Some side effects are missed</td>
</tr>
<tr>
<td>Better adherence to medication</td>
<td>Hospitalizations could increase</td>
</tr>
<tr>
<td>Anxiety is reduced</td>
<td>Anxiety increases resulting in more phone calls to the office</td>
</tr>
<tr>
<td>Trust is increased as is satisfaction with care</td>
<td>Trust decreases as does satisfaction with care</td>
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NCI-ASCO Teams
Communication is essential

- Patients expect to be cared for by individuals who communicate, coordinate and cooperate effectively.

- Care Team members need to have a shared language with the patient and their caregiver.

- Advocates can offer lay language descriptions that fit the patient experience.

- This leads to more meaningful interactions and less confusion and misunderstanding.

NCI-ASCO Teams
Questions Advocates Ask?

- Could consideration of cancer care through patients’ eyes improve outcomes?
- How should a patient be included in the team?
- Is the caregiver a member of the team?
- How should patients be educated/informed about the team?
- How does having the patient as a member of the team enhance outcomes?
- How do we keep all the members of the team informed?
BE SURE TO INCLUDE AN ADVOCATE ON YOUR TEAM!