The Value of Patient Advocacy in Laboratory Research--Making an Impact on Metastatic Breast Cancer Through the Rapid Autopsy Program

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Understanding Metastatic Breast Cancer

- Is the capacity to metastasize an intrinsic property of the neoplasm, or an acquired feature?

- Are all cells in a primary carcinoma capable of metastasis, or just a small subset (subclone)?

- Are different metastases in the same patient biologically different?
Current understanding and practice is hindered by lack of tissue

• Usually only one of the sites of metastasis is biopsied, often by image-guided fine needle aspiration, only obtaining a few cells.

• Metastatic disease growing in different organ sites are assumed to display the same characteristics of ER/PR and HER2neu receptors as the primary tumor or of a single biopsied metastasis. Treatment decisions are based on these findings.
Are these assumptions correct?

- This question and others related to studying biomarkers of the sites where breast cancer has spread were goals of the Rapid Autopsy Study.
- A Tissue Procurement Program was born…
Incorporated into the study was a key role for **PATIENT ADVOCACY**

- When is the right time to discuss this
- Who should be involved
- How should the study be brought up
- Importance of maintaining patient’s rights and dying with dignity…
Membership of Patient Advocacy Task Force

• Lillie Shockney—Adm Director of Breast Center, patient advocate and 2 time survivor.
• Elyse Kaplan—Living Beyond Breast Cancer, survivor
• Karin Noss—NBCC, (succumbed to breast cancer)
• Deborah Kirkland—Young Survival Coalition and survivor
• Frank Adams—MSDBC, Hospice, minister, and father of woman who died of metastatic disease
• Additional participants at the table:
  – Marc Halushka, pathologist; Sara Sukumar—PI of the COE
Decisions: Patient makes the decision; not the family on her behalf

• Advocates wanted to:
  – Ensure her dignity is maintained
  – Promote patient participation in the decision making to enroll in this clinical trial
  – Assess efficiency of body procurement and transfer process from time of death to time of body preparation at funeral home
  – Family feedback regarding the process and interactions with research staff
  – Family’s understanding of purpose of study
Who, how and when do you embark on such a delicate discussion?

- Organ transplant model not the model to use for getting consent for tissue harvesting.
- Needs to be patient’s dying wish.
- Medical oncologist taking care of her needs to ask when it is clear patient understands/accepts that she will succumb to this disease.
- Message— you may be making a difference for the next generation…
Raising Expectations of the Role of the Pathologist

- The word “autopsy” is a scary word.
- Have the pathologist meet with the patient to also discuss the study.
- Ask that the pathologist spend quality time with the patient (and her family) to get to know her and hear her life story/breast cancer journey.
- The pathologist is to explain to the patient that he will be doing this final procedure on her very gently.
Profound experience for pathologist

• Communicating with a “live” patient
• Answering questions about autopsy procedure
• Staying in touch with the patient from point of initially meeting her through to her death, serving as a support person to her – not as “the Grim Reaper”
• Experiencing what it’s like to take care of a patient at end of life….
Measurements of interest to the Patient Advocacy Task Force

- Time from death to time body transported to pathology dept
- Time it took to complete autopsy
- Time from transfer of body to pathology to transfer to funeral home
- Family satisfaction/ perception of the experience
- Communicating results of autopsy if family requests this information
- Funeral directors’ satisfaction with condition of body
- # of patients asked to participate in study
- # of patients who enrolled in study
- Reasons given by patient for declining to participate
Some of our stats--

• 19 patients have been asked; 1 declined.
• Median length of time from death to patient reaching autopsy room is 3 hrs.
• Mean length of time is 3.4 hours
• It takes less than 3 hours for the procedure to be done and the body released to the funeral home.
My personal experience with RAP

- Survivor volunteer—Carolle Anne
- Accompanied pathologist when meeting her and her husband
- Talked with her about why she wanted to participate and what it means to her to do so
- Followed additional interactions pathologist had with patient and family
- Spoke with funeral director about condition of body post autopsy
- Husband interested and willing to talk with other families who are “confused” about study’s purpose and value of this research.
What We Have Learned Already

- Hormone receptors (ER/PR) may become negative in metastases, but there is little variation between different metastases.
- HER2/neu expression is usually the same in primary tumors and their metastases, but not always.
- Gene Promoter Methylation is generally consistent between primary tumors and metastases, and among different metastases. Recovery methylation is a promising potential treatment approach which should be further studied.

Mets BC Retreat

• https://www.youtube.com/watch?v=Bg02G2a7uHo