Jade Moran

My experience at International ILC Symposium 2024

Question: thoughts about what I learned

I came away with a few top-of-mind thoughts:

- Pathology and imaging are the foundation of everything, both are very challenging in ILC, and both need more concerted efforts and attention paid to them. I could be wrong but it's my impression that those specialties attract far less attention and funding than they should considering that they are the fulcrum upon which everything else hinges. Standardizing pathology is critical to getting clean, relevant data from future research; characterizing the different subtypes (and including them in pathology reports) will likely play a big part in that, as well as an increasing use of AI. Improving imaging (or finding reliable alternatives like blood biopsy) is perhaps the most pressing and the murkiest issue facing ILC patients, clinicians and researchers alike. *If we can't find, identify and track the disease then we are hamstrung.*
- Current response criteria (RECIST) used to determine eligibility to enroll in many clinical trials is a roadblock that must be dealt with. We need ILC-specific and inclusive response criteria and we need it fast. In my conversations with Dr. Covington I learned that breast cancer as a whole would benefit from creating and using it's own specific criteria (as prostate cancer has done), but in the absence of that I'm convinced that ILC researchers and advocates should draft their own criteria, to raise awareness of the problem and to get the ball rolling. The ILC community is small, tight-knit and very engaged, I think draft guidelines could potentially be written fairly quickly.

Question: my experience networking with other patient advocates

My time with other advocates was fantastic. The chance to network with advocate friends, to meet others for the first time or the first time in-person, if I'd met them virtually, was so valuable. I've only been an active advocate for 1-1.5 years and to hear the perspectives and experiences of the "veteran" advocates was very helpful.

Question: how will I use this experience and new knowledge in advancing ILC advocacy in the future

The new knowledge, ideas and perspectives I've gotten at the International ILC Symposium will inform and improve my many ongoing advocacy projects and have also sparked some fresh ideas.

My continued and future plans include:

- Writing and speaking about the science and experience of breast cancer from the patient perspective
- Grant review
- Co-lead SHARE's mILC support group
- Advocate to replace RECIST criteria with ILC inclusive, breast cancer specific criteria in partnership with experts in breast oncology, surgery and radiology

- Attend one or more conferences, and raise ILC priorities whenever possible. (ie SABCS, ASCO, SNMMI etc)

Summary of Imaging Session (breakout session 1.2 Tuesday 9/24)
Big takeaway: imaging is a sticky mess in ILC
For screening and detection in early ILC, mammogram is terrible (60% sensitive, 40% false negative–32% size concordance) Ultrasound is middling (70% sensitivity, 30% false negative, 45% size concordance), MRI is quite good (93% sensitivity, 7% false negative, but 30% false positive, 85% size concordance) as is CEM (78% sensitivity, 22% false negative, 8% false positive, size concordance like MRI).
There are many challenges in implementing MRI and CEM.

For metastatic ILC there is a need to image, monitor, and predict tumor response.
FES is very good but it's an "open question" about how to use it. It has some limitations if ER is downregulated or SERDs are in use).
FAPi PET looks promising (especially in the gut which is hard to image).
"Currently imaging can't be used to accurately predict tx response"
There is a huge measurability problem (ILC is often considered "unmeasureable per RECIST criteria, excluding ILC patients from trials) and we need new methods (maybe blood biopsy?) to help make clinical decisions about treatment
There are many novel imaging agents in the pipeline, theranostics looks to be a game changer.

MRI is more accurate than clinical examination, mammo, and ultrasound in monitoring response to neoadjuvant therapy. Earlier detection of progression triggers more timely treatment change. Challenges are that it's not great at assessing residual disease because of ILC's diffuse growth pattern.

We lack data on tumor response evaluation by MRI in ILC due to small representation in research studies, often preventing subgroup analyses

Problem of delayed enhancement of residual tumors and ILC tumors, limits detection on MRI and CEM, need extended studies to capture late-phase enhancement

Whole Body Diffusion Weighted MRI is being used in the clinic in Europe but not US, provides info re differences in cellular density and water mobility between benign and malignant tissue and uses no iv contrast which is especially good for pregnant people and others who can't tolerate contrast.

MRI is better than CT, same or better than FDG, and preferred for lobular & bone/liver
But PET/CT is superior for lymph nodes, lung, and soft tissue.
There is a catch 22 in that it is better to stick to one imaging modality for best comparisons BUT how do you know if you are using the one that is best for your tumor if you don't try all? The speakers did not have an answer for this.

Summary of Metastatic ILC Session (breakout session 2.1 Wednesday 9/25)
Liquid biopsy and ctDNA are emerging options for monitoring mILC. They have some advantages compared to tissue biopsy (non invasive, information from the whole body) as well as some disadvantages (only DNA biomarkers, sometimes non-detectable etc). They can be used in screening/diagnosis, detection of minimal residual disease, treatment response and early diagnosis of recurrence. There are a variety of techniques/tests, some are personalized and some are tumor agnostic, these types of tests are called Next Generation Sequencing (NGS). Limitations are that “deep” sequencing is too costly but “shallow” sequencing can miss uncommon ctDNA.
These technologies might help with the missed/late diagnosis problem in ILC.
So far there is no consensus on whether they should be used serially to watch for progression and guide treatment changes.
Research is being done to examine the utility of NGS with biofluids besides blood, for example, pleural effusions, urine, bone marrow etc.

There are big challenges in regards to ILC and clinical trials due to the “unmeasurable” metastatic burden in ILC, which leads to exclusion and lack of good data. Equally challenging is physicians' overall low awareness of ILC. Patients must often educate their providers.

There was discussion about how Artificial Intelligence (AI) might be used in ILC to address issues of late and missed diagnoses.

One reason that these tests are important to mILC patients is that they can be useful to determine correct treatments re: the patients mutations/resistances. ctDNA is also useful to assess for Leptomeningeal disease.