Breast Cancer Cohort Meeting

- Early on
  - Data set includes survey responses and hospital oncology information
  - Created some policies to ensure thorough involvement and review
  - We accepted 10-12 paper proposals that were approved at the beginning
    - 8 teams are here to present the results of their papers today
- What will be the next study/grant proposal?
  - Are there any common themes we should build on?
  - Is there more dissemination issues we should be focusing on?
- Betsy – Chronic upper extremity disability between breast cancer treatment and quality of life
  - Prevention of these outcomes are often not discussed
  - Quality of life is often affected by this and should be considered
  - Relationship between treatments and quality of life need to be examined
  - UED creates great difficulties for these patients in normal everyday activities
  - Quality of life was researched in the survey
    - Mean UED quality of life score was 5 points lower than the rest
    - Some specific groups are affected by lower quality of like than many more advantaged groups
  - Bilateral mastectomy was significantly related to UED and had a significant impact on their quality of like
  - Prevention surveillance needs to be a much bigger part of treatment considerations
- Amy Trentham-Dietz – Health literacy and perceived care coordination among breast cancer survivors
  - Survey measured understanding of health literacy – lower scores contributed to much worse outcomes for patients
  - Women with higher healthy literacy had greater reported care coordination
  - Having a care coordinator showed to have great benefit for patients with low healthcare literacy
- dReconstruction and Autologous Fat Grafting
  - Two papers
    - Predictors of receiving breast reconstructions
      - Young age, low BMI, high income, employment etc.
      - Age and income were most significant
    - Fat grafting and differing characteristics
      - Most patients did not receive fat grafting, but we do not have much information on these individuals
      - Bilateral mastectomy and flap reconstruction patients were less likely to receive fat grafting
- Brad McDowell – survivor plan usefulness
  - Inspiration was that it is not clear whether survivorship care plans have beneficial effects
  - Are inconsistent findings due to subgroup effects?
  - Some benefit more from survivorship care plans that others
- Did they receive written instructions on where to return for follow up?
  - Health literacy scores were also considered in the same way as in Amy’s paper
  - Survivorship care plans and high health literacy are associated with better wellbeing
  - Having one coordinated is associated with a higher sense of wellbeing
- Mary Schroeder – Breast cancer surgery decision making: comparison of attitudes, treatment goals and outcomes of patients in a collaborative clinical research network
  - Constricted to only those who had unilateral disease
  - Interested in comparing two sets of groups to one another rather than all 3 to each other
  - Goals for therapy was surveyed
    - The most important factor was preventing recurrence
    - What factors would patients prefer doctors play in their treatment decisions
      - Of these we studied in each group who was satisfied with that they got
    - Women getting CPM had to advocate for themselves quite a bit in order to receive it
    - CPM group who had the most expensive surgery and wanted to prevent the most, were must less worried about recurrence after treatment
  - Sample of about ~700 patients were utilized
  - Study would have been even better if we could have looked at before compared to after
- Factors associated with Genetic Testing in a Cohort of BC Survivor
  - Looked for correlations with genetic testing
    - Younger age
    - Higher income and education
    - Private insurance
    - More relatives with breast cancer
    - Urban environment
  - In future studies we need to try to be more inclusive of different populations
- Ann Berger – Preferences and actual chemotherapy decision-making in the GPC Breast Cancer study
  - Article was published on ePub
  - First question on the survey was very broad, second question was to recall patients participation in therapy methods
  - Then went on to examined perceived quality of care and outcomes
  - Have of the women on both sides said they preferred joint decisions discussed with care provider
  - Patients who had more patient-centered decisions eventually led to greater wellbeing and satisfaction with their treatment
  - A more systematic way of going through decision process would benefit both patients and caregivers so as to make sure to collect and consider patient preferences and opinions
- Very good quality survey that led to some great papers – very impressive
  - When patients are involved with researchers the important questions are much more likely to be included
- What led to rural vs urban questions?
o Telemedicine is often used in rural practices
o Access to using codes for rural vs urban was not part of the original IRB, but was added as rural communities do not have as much access to quality healthcare, and this could have been an important variable to consider
o This distinction did not affect some factors but did have an impact on others
o In order to keep survey to a length that would generate a good response rate, some of the items were taken out individually
o Idea of patients reporting quality of care, there is little information in the literature on this
  ▪ Only a few questions asked about results of care etc. that were not very relevant for patients interested in improving quality of care
• Would it be helpful to all groups to know what journals everyone is submitting to?
  o There could be overlap in who is turning in papers on the same topics to the same places
• Would a multi-purpose underlying cohort be useful to create?
  o Could help analyze data and select sub populations to do more specific research on
  o Mary Schroeder submitted a paper that would include participation by five different GPC group
• What are the types of people and why are they dropping out of certain types of care? Do we plan to study this?
  o What are doctors doing about patients wanting to avoid unlivable side effects? Doctors often do not address these
  o Patients in this situation often drop out very early. What can we do to help them continue to take these?
  o This has been studied but not incorporated into clinical practices as much as they should be
  o UED is not addressed in medical records even though we know that more than 50% of patients have it
• RCR is working on bringing in molecular testing orders and learning a bit about the test results
  o The test orders generate a bill and a code and you can find CPT codes for them, but there is a lot of variability