Phyllodes Patients’ Perceptions of Care: Do They Trust Their Doctors?

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Background
- Phyllodes tumors account for <1% of breast tumors
- Management of phyllodes tumors varies widely
  - Benign/borderline phyllodes tumors may not require revision surgery even with positive surgical margins

Specific Aims
- Examine phyllodes management and outcomes across the world
- Study patients’ perceptions of their care

Diagnosis and Management
- 87% biopsied prior to surgery
- FNAs significantly less likely to diagnose phyllodes (43%, p=0.028)

Data Collection
- REDCap survey

Participants
- Online phyllodes support group
- 93 women in 10 countries

Demographics
- Average Age at Dx: 44
- 32% benign, 26% borderline, 43% malignant
- 21% had recurrence (83% local, 17% distant)

Outcomes/Perceptions
- No significant association between recurrence and initial margin positivity (p=0.059) or tumor classification (p=0.321)
- 79% of patients thought surgical margins should be ≥1cm for benign phyllodes tumors
- Most believed the follow up frequency for benign tumors should be every 6 months

Conclusions
- Patients overwhelmingly trust other patients and the Internet over their doctors
- Patients express preference for more aggressive management
  - They prefer wider margins even for benign tumors

Future Directions
- Engage patients in building collaborations in care
- Conduct focus groups and interviews to better understand patient experiences and opinions
- Educational interventions can be targeted at combating common misconceptions about phyllodes tumors

Please email sli1@mgh.harvard.edu with any questions or comments