**Barriers and Facilitators of Active Surveillance: Informational and Emotional**

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**OBJECTIVE:** To determine providers’ views on AS for patients diagnosed with PTMC prior to surgery

**Methods**

**Cohort:** Endocrinologists (n=12) and surgeons (n=12) who treat patients with thyroid cancer

Mixed-methods study:
- Semi-structured interviews, audiotaped and transcribed
- Brief survey about attitudes for AS

**Example Questions**

1. Tell me about your response to the 2015 ATA Guideline changes, including AS as an appropriate treatment for PTMC?
2. What concerns do you have about AS?
3. What are the challenges of implementing AS?
4. What factors shape what treatment option you recommend for patients with PTMC?
5. What do you tell patients about the pros and cons of treatment options for PTMC?
6. How do patients react to the different treatment options for PTMC?
7. In your experience, what outcomes are most important to patients?

**Analysis:**
- Verbatim interview transcripts coded using NVivo©
- Thematic content analysis until we reached saturation (n=19)
- Descriptive statistics of survey

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**Results**

**Table 1: Provider Demographics**

<table>
<thead>
<tr>
<th>Age (mean, range)</th>
<th>47 (34-68)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>17 (70.8)</td>
</tr>
<tr>
<td>Caucasian</td>
<td>21 (87.5)</td>
</tr>
<tr>
<td>Academic practice</td>
<td>21 (87.5)</td>
</tr>
<tr>
<td>Location</td>
<td></td>
</tr>
<tr>
<td>East/Northeast</td>
<td>10 (42)</td>
</tr>
<tr>
<td>South</td>
<td>4 (17)</td>
</tr>
<tr>
<td>Midwest</td>
<td>8 (33)</td>
</tr>
<tr>
<td>West</td>
<td>2 (8)</td>
</tr>
<tr>
<td>Treat &gt;10 PTMC/year</td>
<td>16 (68)</td>
</tr>
<tr>
<td>&gt;50% of endocrinology practice is thyroid cancer</td>
<td>6 (50)</td>
</tr>
<tr>
<td>&gt;20 thyroid surgeries/year</td>
<td>12 (100)</td>
</tr>
<tr>
<td>Member of the ATA</td>
<td>24 (100)</td>
</tr>
<tr>
<td>Read all of 2015 ATA guidelines</td>
<td>16 (68)</td>
</tr>
</tbody>
</table>

*Self-reported

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**Barriers and Facilitators of Active Surveillance (AS)**

**Barriers**
- “Patients feel more comfortable with a total”
- “There’s a gut reaction...you can’t watch a cancer”
- “With surgery you don’t have to worry or think about it”
- “…someone is going to have an adverse effect”
- “I know the data, but I still worry about the 1% or less risk of mets...”

**Facilitators**
- “I say...I don’t think surgery is necessary...You can’t take [surgery] back. With AS...it’s not a permanent decision.”
- “They don’t have to make a decision today...we don’t miss the boat by waiting.”
- “I tell them the prognosis is excellent, they’re more likely to die getting hit by a taxi...”

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**Figures: Survey Analysis**

- I know enough about the treatment alternatives for PTMC
- I explain active surveillance as an option for PTMC
- Treatment decisions about PTMC are hard to make
- I would use a decision aid if it was easy and quick

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**Conclusions**

- **Barriers to active surveillance include:**
  - Emotional reaction to “cancer”
  - Fear of poor outcomes or metastasis
  - Uncertainty about cancer outcomes
  - Practice limitations (i.e., resources; ultrasound quality)
  - Patient and disease factors

- **Facilitators of active surveillance include:**
  - Reassurance by providers
  - Patient fear of surgery and complications
  - Patient avoidance of thyroid hormone replacement

- **Use of a decision aid may facilitate implementation of active surveillance**

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Patients' and Providers' Reactions to a PTMC Diagnosis

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Introduction

- We have previously shown that patients with papillary thyroid cancer >1cm have a strong urge to “get it out.”
- The immediate impact of a papillary thyroid micro-cancer (PTMC), tumors 1 cm or smaller, diagnosis on these patients and providers is less well understood.

Objective: To examine PTMC patients’ and providers’ reactions to this diagnosis.

Methods

Cohort: Patients with PTMC (n=10), Endocrinologists (n=12), Endocrine and ENT surgeons (n=12)

Semi-structured Interviews:
- Open-ended, semi-structured interviews
- Trained non-clinical interviewers with piloted guide
- Mean duration: 43 mins (range 45 - 120)
- Patient interviews 9-60 months post-operatively

Analysis:
- Verbatim interview transcripts coded using NVivo©
- Thematic content analysis of transcripts until saturation was reached (n=21)

Results

Table 1: Patient Demographics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n (%)</th>
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</thead>
<tbody>
<tr>
<td>Mean Age (range)</td>
<td>46.5 (21-77)</td>
</tr>
<tr>
<td>Female gender</td>
<td>8 (80)</td>
</tr>
<tr>
<td>Caucasian</td>
<td>9 (90)</td>
</tr>
<tr>
<td>Currently employment</td>
<td>8 (80)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Some college/Associate degree</td>
<td>4 (40)</td>
</tr>
<tr>
<td>College graduate</td>
<td>3 (30)</td>
</tr>
<tr>
<td>Post-graduate degree</td>
<td>2 (20)</td>
</tr>
</tbody>
</table>

Table 2: Provider Demographics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Age (range)</td>
<td>47.2 (34-68)</td>
</tr>
<tr>
<td>Female gender</td>
<td>9 (37.5)</td>
</tr>
<tr>
<td>Caucasian</td>
<td>21 (87.5)</td>
</tr>
<tr>
<td>University/Academic center</td>
<td>21 (87.5)</td>
</tr>
<tr>
<td>Treats 11+ PTMC patients/year</td>
<td>16 (66.7)</td>
</tr>
<tr>
<td>Has read ALL of 2015 ATA guidelines</td>
<td>16 (66.7)</td>
</tr>
</tbody>
</table>

Table 3: Quotes exemplifying reaction to diagnosis

**Patient**

- “Cancer is a really scary word to hear...My mom had a bigger reaction...really upset just knowing that it’s the word cancer.”
- “No one can predict with 100% certainty that it’s not going to grow, or it’s not going to spread...so that’s why I lean more towards, ‘let’s just get it out.’”
- “You hear ‘cancer’ and your mind automatically goes, ‘I need it out.’”
- “I don’t want to sit back and wait...I want something done.”

**Provider**

- “I think actually doing surgery is better. Just to sort of have something finite and taken out”
- Patients hear “cancer” and they want something done”
- “I’m not comfortable watching a cancer.”
- “Cancer is cancer...they get scared, they get anxious about what’s coming.”

Conclusions

- Reactions to a PTMC diagnosis are greatly influenced by the word “cancer.”
- Following diagnosis of PTMC, patients and providers have a reflex desire to “get it out” regardless of the tumor size or indolent nature.
- The reflex desire to “get it out” likely plays a role in the decision-making and overtreatment of patients with PTMC.
- Understanding these reactions may facilitate less extensive treatment of patients with PTMC.

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