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A Qualitative Analysis of Medical Decision-Making Experience in Papillary Thyroid Cancer

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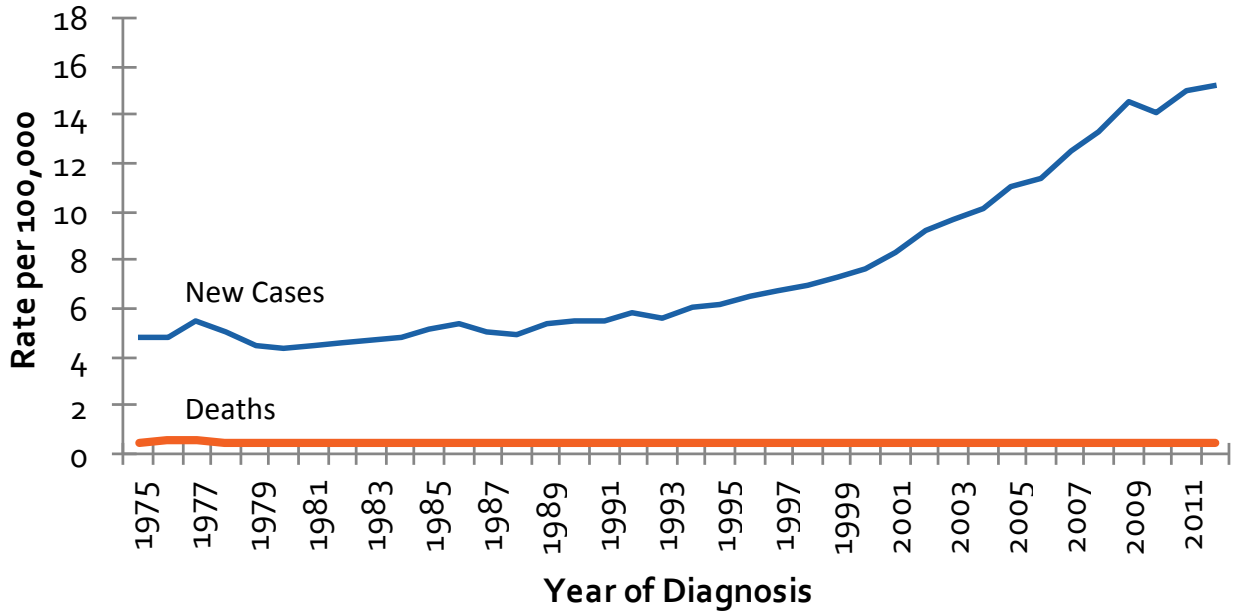
Incidence of Thyroid Cancer

- Dramatic rise in thyroid cancer incidence (Davies & Welch, 2014; Enewold et al., 2009)
  - 1975 = **4.73** per 100,000
  - 2012 = **15.23** per 100,000
- Mortality rates have remained stable
- Attributed to advances in imaging technologies and screening methods

Thyroid Cancer Rates, 1975-2012



Source: SEER Program, National Cancer Institute (http://seer.cancer.gov/registries/terms.html)

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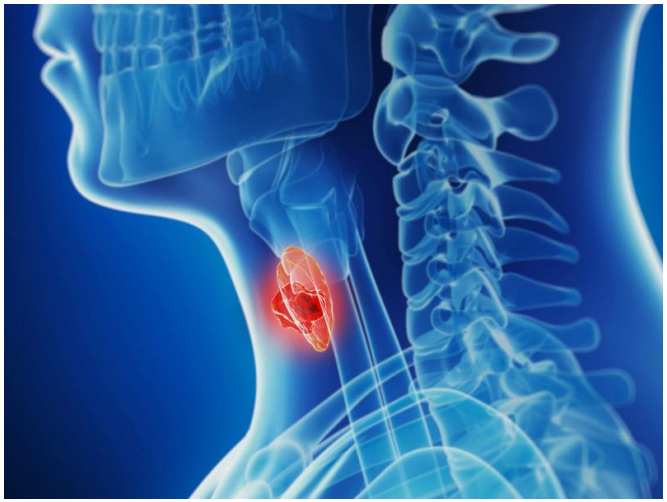
Papillary Microcarcinoma (PMC)

- 50% of all thyroid cancer cases
- Localized disease
- Tumor ≤ 1 cm in diameter
- Favorable prognosis (Hay, 2007):
  - Disease-specific mortality < 1%
  - Loco-regional recurrence 2-6%
  - Distant recurrence 1-2%
- Up to 17 million Americans unknowingly have PMC (Ross & Tuttle, 2014)

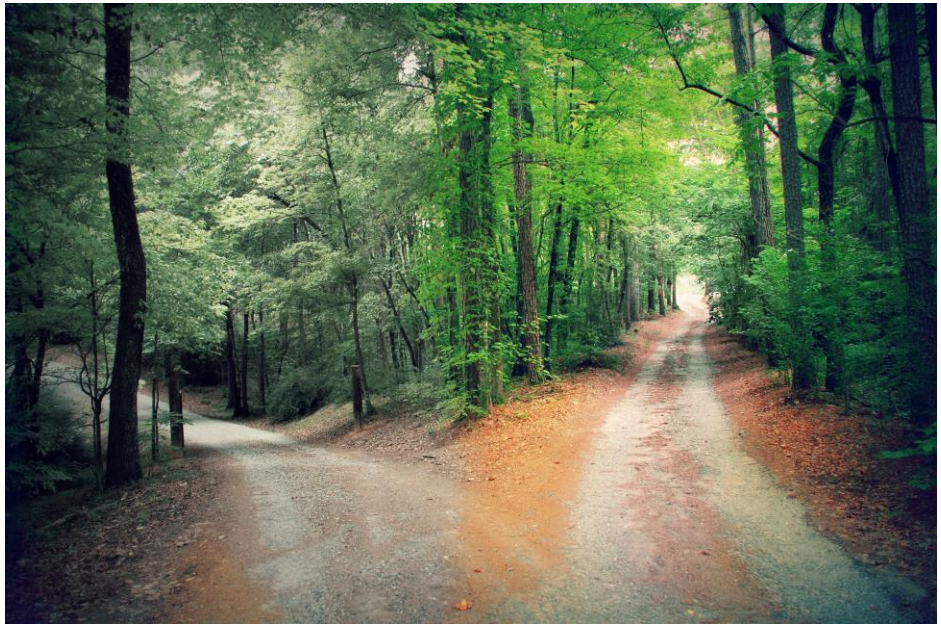


PMC Treatment Options

- American Thyroid Association (ATA)
  - *2015 Management Guidelines for Adult Patients with Thyroid Nodules and Differentiated Thyroid Cancer* (Haugen et al., 2015)
- ***Active surveillance*** = closely monitor disease with imaging at 6 month follow-up intervals; postpone surgery until disease progression is noted
  - Japanese trials have demonstrated comparable outcomes to surgery (e.g., Ito et al., 2010)

Current Study

- Objective:
  - To develop an in-depth understanding of PMC patients' decision-making experience when offered initial treatment options of active surveillance and surgery



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Methods

- *Recruitment and Data Collection*
  - Inclusion criteria:
    1. Diagnosis of PMC or subcentimeter thyroid lesion suspicious for PMC within past year
    2. Offered options of active surveillance and surgery
    3. English speaking
    4. ≥ 18 years of age
  - 33 patients approached and 15 enrolled (acceptance rate = 45.5%)
  - 6 significant others were enrolled
  - Focus groups (n = 4) and individual interviews (n = 7)
- *Analysis*
  - Thematic text analysis

Study Sample

- **Surgery Group**
  - 4 surgery patients and 3 significant others
- **Active Surveillance Group**
  - 11 active surveillance patients and 3 significant others
- Age range = 29 to 69 years old (mean = 48.3)
- Predominantly:
  - Female (93.3%)
  - White (93.3%)
  - Married (60%)
  - > High school education (66.7%)
  - Diagnosed < 6 months (66.7%)

Results: Surgery Group

- A Swift Decision
- General View of Cancer
- Risks of Active Surveillance
- Eradication of Disease

Results: Surgery Group

- A Swift Decision
  - Intuition
  - Urgency

"In my case I just knew in my heart, 'No, I just want to remove it,' and that was it."

"There was no other choice. It wasn't even a decision. It was just what had to be done."

"No matter what, I think you just go with your gut…"

"My decision was kind of quick. I didn't have any fear…I was sure it was going to be fine."

Results: Surgery Group

- General View of Cancer
  - Beliefs, expectations, and fears
  - Impact of previous experiences

"Cancer is cancer."

"Just the word cancer is scary."

"I thought of it more as cancer in general. I knew it was not the same as having breast cancer or something. I knew it was not quite as serious. But I didn't care. It was cancer. I wanted it out, no matter what."

"My little brother died of cancer. I've always been afraid of getting cancer. As soon as I heard I had it, it was, 'Get it out.'…I've watched it and I've seen the horror."

Results: Surgery Group

- Risks of Active Surveillance
  - Fear of disease progression

"Watching could literally be deadly."

"I think if it's in there it's going to go somewhere else."

"All it can do is get worse by being in you…Even if it's teeny, teeny tiny, over ten years, it's growing."

Results: Surgery Group

- Risks of Active Surveillance
  - Fear of disease progression
  - Surgery as inevitable

"If it's eventually going to have to come out, then you might as well do it now. If it's cancer it's always going to be cancer. Cancer doesn't just go away on its own."

"Ultimately, it's going to come out. So why not do it now?"

Results: Surgery Group

- Risks of Active Surveillance
  - Fear of disease progression
  - Surgery as inevitable
  - Experience of uncertainty

"Nausea. Stress. I had such an uneasy feeling knowing it was there."

"I didn't want to live life worrying about my body every day, thinking, 'What if?' You know? 'What if? What if? What if?' So I just wanted to get rid of it and then live a normal life."

"If it's something you can control why not control it? As opposed to waiting, you're not in control. You're doing screenings every six months, every year. In between you have no control."

Results: Surgery Group

- Eradication of Disease
  - Physically removing the cancer
  - Chance for cure

"And I'll be honest, I really had no question in my head. It's cancer, get it out. It was just, 'I have cancer, get it out.'"

"Cancer…it just has no place in my body."

"If you have cancer in your body, you have to get it out."

"I just wanted to be clean."

"Every doctor made it sound as if after the surgery that's it. This one's treatable. This one's curable. Just take it out and that's it."

Results: Active Surveillance Group

- Perception of PMC
- Valued Function and Role of the Thyroid
- Comfort with Active Surveillance

Results: Active Surveillance Group

- Perception of PMC
  - Indolent disease ("good" cancer)
  - Common

"Well-behaved in the sense that…it's the slowest growing. It doesn't spread quickly…It really takes a lot of neglect for it to get rampant, if at all."

"It means not sure…could be, couldn't be…So I kind of put this over in a special little box."

"I don't know, cancer, but kind of an annoying one that if I didn't look it wouldn't bother me."

"There's a lot of people in the United States that have it…they usually find thyroid cancer during autopsies. So it's very common."

Results: Active Surveillance Group

- Valued Function and Role of the Thyroid
  - Physical functioning and QOL ramifications
  - Experience of loved ones

"Your thyroid is not your tonsils. It's not your appendix…It's an important part of your body and I felt it warranted a little more thought, you know? Everyone hears cancer and they get scared and they were kind of pushing me in the direction of having it removed and 'Don't worry about it anymore.' But my thought process was, it's not that easy. There is something else or maybe more than one thing that I'll have to worry about if I have it removed along with my thyroid."

"What does scare me is, what happens if you get your thyroid out and then you have trouble regulating your body?…it's better if your body can take care of itself. So that's my concern with surgery, I'm more concerned with just how your body functions without the thyroid afterwards."

Results: Active Surveillance Group

- Comfort with Active Surveillance
  - Ability to tolerate uncertainty
  - Ongoing decision-making progress

"But you know, life moves on and this seamlessly stays in the background."

"I think that I'm probably more likely to have a heart attack with certain aggravations that I have in my life than I do of this really affecting me."

"I kind of have an optimistic attitude about things to say, well, let me see. You can always go for the surgery when things get worse."

"And no one is telling me that it actually is not going to spread. It can spread. So I'm not saying that I'm not having it out, just at this moment I'm not having it out."

Results: Similarities

- Trust in Physician and Institution
- Sources of Information

"For him it's a Tuesday morning….It's, 'I've done these my whole life. It's no big deal. We'll get you in, we'll get you out.' And that's it."

"He's a researcher and he does these things every day. He sees these things every single day. He flies and goes all around the country…he knows what he's talking about. I felt comfortable that he knows what he's talking about and so did my husband."

"Obviously, I'm probably in one of the best, if not the best place for cancer in the country. For research and care in general…I'm probably at the best place I could possibly be…It gives me a level of comfort, for sure."

Conclusions

- Impact of multiple factors
- Similarities and differences noted between treatment groups
- Consistent with localized prostate cancer decision-making (e.g., Anandadas et al., 2011; Oliffe, Davison, Pickles, & Mroz, 2009; O'Rourke, 1999)
- Appraisal and management of risk and uncertainty (Mishel, 1988; Mishel & Clayton, 2003)

Conclusions

- *Limitations*
  - Sample diversity
  - Retrospective review
  - Objective measures
  - Size of surgery group

- *Future Directions*
  - Longitudinal study
  - Role and experience of significant others
  - Development of educational resources and support tools

Team Members

- **Carma L. Bylund, PhD,** Hamad Medical Corporation; Memorial Sloan Kettering Cancer Center
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