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Treatment Decision-Making in Early-Stage Papillary Thyroid Cancer

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Abstract

Objective—The purpose of this study was to develop an in-depth understanding of papillary microcarcinoma (PMC) patients' decision-making process when offered options of surgery and active surveillance.

Methods—15 PMC patients and six caregivers participated in either a focus group or individual interview. Focus groups were segmented by patients' treatment choice. Primary themes were identified in transcripts using thematic text analysis.

Results—Four themes emerged from the surgery subsample: (1) Decision to undergo thyroidectomy quickly and with a sense of urgency; (2) Perception of PMC as a potentially life-threatening disease; (3) Fear of disease progression and unremitting uncertainty with active surveillance; and (4) Surgery as a means of control and potential cure. Three themes emerged from the active surveillance subsample: (1) View of PMC as a common, indolent, and low-risk disease; (2) Concerns about adjusting to life without a thyroid and becoming reliant on hormone replacement medication; and (3) Openness to reconsidering surgery over the long run. Two themes were identified that were shared by participants from both subsamples: (1) Deep level of trust and confidence in physician and cancer center; and (2) Use of physician and internet as primary sources of disease and treatment-related information.

Conclusions—Several factors influenced participants' treatment choice, with similarities and differences noted between surgery and active surveillance subsamples. Many of the emergent themes are consistent with research on decision-making among localized prostate cancer patients. Findings suggest that participants from both PMC treatment subsamples are motivated to reduce illness and treatment-related uncertainty.

Introduction

The incidence of thyroid cancer in the United States has tripled over the past several decades, drastically rising from 4.9 per 100,000 in 1975 to 14.3 per 100,000 in 2009. The rapid growth in thyroid cancer has been attributed to a dramatic rise in the diagnosis of

papillary microcarcinoma (PMC), a form of papillary thyroid cancer with a tumor size < 1 cm. 1,2 The percentage of new thyroid cancer diagnoses that were PMC grew from 25% in 1988–89 to nearly 40% in 2008–2009. PMC is believed to be extremely common, with conservative estimates suggesting that as many as 17 million Americans have PCM unknowingly. $^{3-5}$ PMC is also considered low-risk, with disease-specific mortality less than 1%, loco-regional recurrence rates between 2–6%, and distant recurrence rates of 1–2% among patients who completed surgery without adjuvant therapy. 3,4

While surgery has traditionally been the recommended approach in managing PMC, newly released American Thyroid Association guidelines support active surveillance in very low-risk thyroid cancers. Active surveillance refers to a form of expectant management in which a cancer is closely monitored over time via imaging. Physicians in Japan have offered active surveillance to PMC patients over the past two decades with comparable outcomes as compared to surgery. For example, findings from observational studies suggest that observing PMC over time carries minimal risk of disease progression and incurs no increase in disease specific mortality in properly selected patients. 4,9,10 At the same time, thyroidectomy poses limited risks: 1–2% risk of permanently impaired vocal cord function, 2–3% risk of permanent hypocalcemia, 1% risk of infection, and a 1% risk of death. Clearly the objective risks and benefits of surgery versus active surveillance for PMC are similar and a superior treatment approach is equivocal.

In spite of the updated American Thyroid Association guidelines, it remains unclear whether or not patients in the United States would seriously consider active surveillance as an acceptable management option for PMC. No studies on patients' preference for active surveillance versus surgery have been conducted in the United States. Patients' choice of treatment in Japanese trials suggests that active surveillance has become increasingly accepted over time. For example, only 24% of enrolled PMC patients opted for active surveillance in one Japanese trial between 1993 and 2004.8 More recent data shows that 55% of patients chose active surveillance when presented with the option. Many patients still appear highly motivated to remove their thyroid when cancer is detected. At the same time, if patients consider the aforementioned minimal risks of disease progression and metastasis in light of surgical risks and other factors, active surveillance may be an appealing alternative.

To the best of our knowledge, no empirical studies have examined treatment decision-making among PMC patients. Such a gap in the literature is problematic given the dramatic rise in the number of Americans diagnosed with PMC over the past several decades and the fact that an increasing number of PMC patients in the United States will be faced with a choice between active surveillance and surgery as a result of the newly released treatment guidelines. Research investigating how PMC patients weigh the risks and benefits of initial treatment options is a crucial first step in determining how to best meet the informational needs of this unique cancer population and aid in informed decision-making. The purpose of this qualitative study was to develop an in-depth understanding of PMC patients' decision-making approach when offered a choice between active surveillance and surgery.

Methods

Recruitment and Data Collection

Participants were recruited from an endocrinology outpatient clinic at Memorial Sloan Kettering Cancer Center. Eligible participants were: (1) diagnosed with PMC within the past year; (2) offered treatment options of active surveillance and surgery; (3) English speaking; and (4) 18 years of age. A total of 33 patients were approached and 15 agreed to participate (acceptance rate = 45.5%). Patients' primary reasons for study refusal included lack of interest, significant geographic distance from the study site, being too busy, and too anxious to discuss their illness.

Enrolled patients were asked if they would like to nominate a caregiver who assisted their decision-making process to also participate. We included caregivers for two reasons. First, it is well-established that a cancer diagnosis profoundly impacts not only the patient, but also his or her family members. ^{12,13} Second, cancer patients do not make treatment decisions in isolation. Caregivers frequently attend oncology appointments and help patients with their decision-making process. ¹⁴ For these reasons, we believed that caregivers held an important perspective on how patients approached decision-making and arrived at a treatment choice. Six caregivers were nominated and enrolled in this study. Therefore, the total sample included 21 participants. This study was approved by the Institutional Review Board at our institution (registration number 00000273) and informed consent was obtained from all participants. Each participant was compensated \$50 for their time.

After consenting to the study, participants were scheduled for a focus group. Individual interviews were offered as an alternative to individuals who were unable to attend any of the scheduled focus groups. We believed that this option would help address barriers to participation and therefore improve accrual rates. We segmented the focus groups by patients' treatment choice, either surgery or active surveillance. Caregivers were interviewed alongside the patient who had nominated them. A total of three focus groups (one surgery and two active surveillance) and seven individual interviews (two surgery and five active surveillance) were conducted. Of the 15 PMC patients who participated in the study in total (across both focus groups and individual interviews), four were from the surgery subsample and 11 were from the active surveillance subsample. Of the six caregivers who took part in the study, three were from the surgery subsample and three were from the active surveillance subsample.

A qualitative methods specialist (ES) moderated each focus group. Individual interviews were conducted by a research fellow (TD) and supervised by the qualitative methods specialist. The research fellow is a clinical psychologist with interest and experience in research on doctor-patient communication, treatment decision-making, illness experience, and survivorship in the cancer setting. Each focus group or individual interview lasted approximately 60–90 minutes. Semi-structured interview guides were created to explore the following topic areas: perceptions of PMC and disease status; treatment decision-making processes and influential factors in decision-making; sources of information used in decision-making; and perceived barriers and facilitators to surgery and active surveillance.

All focus groups and individual interviews were audio recorded and transcribed by an external transcription service.

Data Analysis

The fellow analyzed all transcripts using thematic text analysis. ^{15,16} The ATLAS.ti program was used to organize and analyze all data. ¹⁷ Transcript excerpts were initially coded into as many thematic categories as possible through open coding and constant comparison. Memo creation was an important component of the open coding phase as well as throughout the coding process. Memos refer to detailed notes on the ideas and thought processes of the coder, which serve to uncover the properties of a thematic category and allow for development of rules regarding thematic category assignment. ¹⁸ As coding became more rule-oriented, an iterative process of identifying, defining, testing, and refining thematic categories was utilized. ¹⁹ In the final phase of coding, fewer and fewer modifications to thematic categories were made and memos reflected the overarching scope of understanding concerning the structure of the decision-making process for the active surveillance and surgery subsamples. In addition, similarities and differences in treatment decision-making processes between the subsamples were noted. ¹⁸

An expert panel was formed to guide the fellow's analysis and included an endocrinologist and nurse practitioner with expertise in treating PMC (RMT and RZ), two behavioral scientists with research experience in healthcare decision-making and communication (EM and CB), and the qualitative methods specialist. Expert panel members met with the fellow on a regular basis and provided feedback concerning the fellow's thoughts, observations, and emerging conclusions.

After the analysis was completed, a member check was conducted in which interpretations and conclusions were shared with participants to obtain feedback and as a means to attain trustworthiness in the thematic findings. Two summary documents were created that outlined the themes and properties of each thematic category for each treatment subsample. Participants received a copy of the summary document that corresponded to their treatment subsample in the mail. Follow-up interviews were then completed via telephone, offering participants an opportunity to discuss the relationship between research findings and their lived experience, as well as to correct errors or misunderstandings that may have emerged during data collection or analysis. Sixteen participants completed a follow-up interview, including 12 patients and four caregivers. Overall, participants who completed a follow-up interview reported that the findings were consistent with their experience. Therefore, no themes were added or modified based on the member check.

Results

Study Sample

Patients ranged in age from 29–69 years old (mean=48.3 years). Patients were predominately female, white, married, educated beyond high school, and diagnosed within the previous 6 months. Caregivers ranged in age from 31–81 years old (mean= 53.2 years)

and were all white males. Caregivers were predominately married and educated with a postgraduate degree. Full demographics are presented in Tables 1 and 2.

Emergent Themes

Four primary themes emerged from analysis of the surgery subsample transcripts and three themes were identified during analysis of the active surveillance subsample transcripts. In addition, two themes emerged that were shared by participants from both treatment subsamples. Themes and supporting quotes are presented in Table 3.

Surgery Subsample Findings

Decision to undergo thyroidectomy quickly and with a sense of urgency—

Selection of thyroidectomy, and confidence in the effectiveness of this treatment, came quickly to surgery participants. Surgery participants sensed immediately that surgery was the "right" treatment and viewed surgery as a necessity rather than option. As one participant stated, "It wasn't even a decision. It was just what had to be done." Surgery participants spoke of feeling intense anxiety immediately after diagnosis and an urgency to undergo thyroidectomy as soon as possible. For example, one patient described a rapid pace from her initial consultation to the operating room, where she filled an open surgery slot and had her thyroid removed less than a week after first meeting her surgeon.

Perception of PMC as a potentially life-threatening disease—Surgery participants expressed a strong set of cancer-related beliefs, expectations, and fears. Positive framing of PMC (i.e., describing PMC as a "good cancer") provided some relief, but any comfort related to the specific diagnosis was overshadowed by these participants' negative views of cancer in general. As one participant stated, "Just the word 'cancer' is scary." Such underlying views were informed by a personal history of another cancer or an experience of loss involving cancer (e.g., one participant lost her brother to leukemia at a young age). As such, any type of cancer was seen as something that should be feared and treated aggressively.

Fear of disease progression and unremitting uncertainty with active

surveillance—It was apparent that surgery participants were unable to consider active surveillance as a viable treatment option during their decision-making process. Surgery participants' general view of cancer contributed to the belief that cancer, by its very nature, progresses. Therefore, these participants reasoned that PMC could only spread as long as the thyroid remained and that active surveillance left an individual vulnerable to disease progression. Surgery participants felt that thyroidectomy was the inevitable outcome and active surveillance was a temporary solution, at best. As one patient said, "If it's eventually gonna have to come out then you might as well do it [now]. If it's cancer, it's always gonna be cancer." In addition, the prospect of active surveillance presented unique emotional concerns for surgery participants. These participants described intense anxiety in the period of time between diagnosis and surgery and so the thought of living with a known cancer indefinitely seemed unbearable. As one patient noted, "I just didn't want to live life worrying about my body every day...thinking 'What if?' You know? 'What if? What if? What if?' What if?' What if?' What if?' What if?' You know? 'What if?' What if?' What if?' What if?' What if?' You know?' 'What if?' What if?' What if?' What if?' You know?' 'What if?' What if?' What if?' What if?' What if?' You know?' 'What if?' What if?' What if?' What if?' You know?' 'What if?' What if?' What if?' You know?' 'What if?' What if?' You know?' 'What if?' You know?' 'What if?' What if?' You know?' 'What if?' You know?' 'What if?' What if?' You know?' 'What if?' Y

Surgery as a means of control and potential cure—Thyroidectomy offered surgery participants a means of control. As might have been expected, a focus on eradicating cancer dominated the decision-making process of PMC participants who selected surgery. As one participant expressed, "If it's cancer, get it out." Another reported, "I wanted to be clean." Surgery participants' emphasis on resection of disease was consistent with a goal of cure and a desire to move past the cancer experience. As one participant said, "I just wanted to get rid of it and then live a normal life."

Active Surveillance Subsample Findings

View of PMC as a common, indolent, and low-risk disease—Active surveillance participants shared the belief that PMC is a "good cancer" or low-risk disease with little to no risk of rapid progression or metastasis. Using terms like "well-behaved" or "annoying", active surveillance participants characterized their disease status as falling somewhere between a benign and cancerous tumor. For example, one participated shared, "Well, to me it means I might [have cancer] or I might not." These participants also perceived PMC as common, which further contributed to a view of PMC as indolent and not life-threatening. As one participant noted, "There's a lot of people in the U.S. that have it…They usually find thyroid cancer during autopsies. So it's very common."

Concerns about adjusting to life without a thyroid and becoming reliant on hormone replacement medication—During their decision-making process, active surveillance participants were most concerned with negative ramifications of undergoing surgery on physical functioning and quality of life and being reliant on hormone replacement medication for the rest of their life. These participants valued the thyroid, which they emphasized as fulfilling an important regulatory function and role. Therefore, active surveillance participants were hesitant to remove such an important part of the body. For example, as one participant stated, "What does scare me the most is, what happens if you get your thyroid out and then have trouble regulating your body?...It's just better if your body can take care of itself." In addition, several participants had witnessed family members or friends struggle after having a thyroidectomy (e.g., with low energy levels or fluctuations in weight). Such experiences colored active surveillance participants' perception of thyroidectomy and served as a warning of the risks of surgery.

Openness to reconsidering surgery over the long run—Active surveillance participants hoped to avoid surgery as long as possible, but ultimately viewed thyroidectomy as an option that they could always return to. As one participant stated, "No one's telling me that it's 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." In this way, treatment decision-making was an ongoing process. Rather than considering PMC as a condition that needed urgent treatment, these participants were comfortable with postponing surgery and reevaluating their preferences regarding treatment over time based on new information from follow-up scans. Additionally, while active surveillance participants were anxious about potential post-surgical complications, these participants demonstrated an ability to live comfortably with the uncertainty that is often associated with an observation approach. As one participant noted, "But you know, life moves on and this seamlessly stays in the background." Such

sentiments recurred in the responses of other active surveillance participants, reflecting the minimal space their disease occupied within their daily thoughts and hierarchy of concerns. As another example, one participant noted:

It's not as though I feel anything or I'm aware of anything...I am what I've always been. I don't think about it...You know, as I walked in the doors for the sonogram that day, I said, 'Gee, this is the first time I've thought about it. I hope everything goes well!' And then I did what I had to do...I'm not dwelling on this.

Common Themes between Subsamples

Deep level of trust and confidence in physician and cancer center—Participants from both treatment subsamples expressed trust and confidence in their physician and cancer center. Participants viewed their treating physicians as experts and leaders in the field. Participants frequently cited their physician's reputation and high volume of patient care as evidence of their skill and expertise. Additionally, surgery and active surveillance participants believed that the cancer center where they received treatment was at the cutting edge of research and treatment. Such views bolstered participants' comfort with their treatment decision.

Use of physician and internet as primary sources of disease and treatment-related information—Surgery and active surveillance participants also utilized similar sources of information during their decision-making process. Participants from both treatment subsamples reported seeking information about PMC and available treatment options from their physician and the internet. At the same time, participants cautioned about relying on the internet as a primary source of information and shared that they frequently filtered web-based information by only going to credible websites. For example, one participant stated, "That's why it's good if you only to go to Sloan Kettering's website or Johns Hopkins or Mayo Clinic. That's the only ones we ever really went to. You know, doctor.com, we didn't go to."

Discussion

The present study represents the first empirical investigation of treatment decision-making in PMC. Preliminary results provide much needed insight into how patients view PMC, weigh benefits and risks of treatment options, and navigate the decision-making process. Findings suggest that several factors influence patients' ultimate treatment preference, with similarities and differences evident between active surveillance and surgery subsamples.

Our findings are largely consistent with research on decision-making in early-stage prostate cancer. For example, active surveillance patients in the current study feared the potential impacts on physical functioning and quality of life that they believed would accompany life without a thyroid. Such findings are comparable to localized prostate cancer patients who are most concerned with potential side effects of more aggressive treatments (e.g., incontinence, erectile dysfunction) and opt for active surveillance. ^{21–23} For surgery participants, fear of disease progression and a desire to eradicate cancer from the body contributed to the decision to undergo thyroidectomy. These findings are similar to data

demonstrating how localized prostate cancer patients select more invasive treatment options such as radical prostatectomy. ^{21,22,24–26} Finally, in contrast to several studies exploring active surveillance patients' experience of living with prostate cancer, ^{27–30} active surveillance participants in our study expressed minimal anxiety concerning disease status.

Consistencies between our findings and existing research on prostate cancer decision-making are not entirely surprising. A great number of similarities exist between early-stage prostate and thyroid cancers. To begin, advances in diagnostic screening technology have resulted in the increased detection and diagnosis of both forms of early-stage cancer. Next, as with PMC patients in the current study, localized prostate cancer patients must choose between more and less aggressive treatment options (e.g., prostatectomy and active surveillance). Moreover, no definitively optimal treatment exists for either group of patients and both must settle on a treatment choice in the face of growing concerns about overdiagnosis and overtreatment.^{31–33} Based on these similarities, and the consistent findings noted above, well-established literature in localized prostate cancer may offer a useful knowledge base to guide future research and understanding in how low-risk thyroid cancer patients choose between initial options of active surveillance and surgery.

The appraisal and management of uncertainty were inherent in the decision-making process of participants from both PMC treatment subsamples. As such, the Uncertainty in Illness Theory^{34,35} can help conceptualize our findings. Uncertainty is defined as an inability to construct meaning or accurately predict outcomes based on illness-related stimuli that are ambiguous, complex, and unpredictable.³⁶ According to the Uncertainty in Illness Theory, uncertainty is said to be a neutral cognitive state and the emotional experiences that are so common in illness (e.g., fear of cancer recurrence) occur only after positive or negative evaluations of illness-related events and information have occurred. Further, an individual may engage in a variety of coping strategies depending on their subjective appraisal of uncertainty. For example, uncertainty can be seen as a threat, causing anxiety or fear of a negative outcome, and result in mobilizing efforts that aim to resolve uncertainty and reduce emotional distress.

Our thematic findings demonstrate that both surgery and active surveillance participants experienced uncertainty, although these treatment subsamples can be differentiated based on the nature that uncertainty and efforts used to manage it. Surgery participants were fearful and anxious about disease progression at the time of diagnosis and when considering the prospect of living indefinitely with a known cancer. Surgery participants considered PMC as potentially life-threatening based on cancer-related beliefs, expectations, and experiences. Such factors ultimately contributed to surgery participants' negative appraisal of uncertainty regarding disease status, which resulted in emotional distress, in turn. Alternatively, active surveillance participants' uncertainty centered on the potential adverse side effects of surgery. Active surveillance participants were most worried about whether or not they could live a normal life and function day-to-day without their thyroid. Our findings suggest that active surveillance participants' view of PMC as prevalent and low-risk enabled them to focus their attention away from concerns over disease status and progression, while other factors such as witnessing family members struggling in the wake of thyroidectomy seemed

to contribute to active surveillance participants' negative appraisal of uncertainty regarding post-surgical adjustment.

In terms of uncertainty management, our findings indicate that thyroidectomy offered surgery participants a chance to resolve uncertainty and emotional distress surrounding disease status. Surgery participants were motivated to eradicate cancer from the body and to return to a life that they had lived pre-diagnosis. Valuing a different set of goals and priorities, active surveillance participants demonstrated an effort to live a life relatively unaffected or uninterrupted by their disease. From this perspective, active surveillance offered these participants an opportunity to preserve a valued part of the body and to avoid feared consequences of surgery.

Study Limitations

Some limitations of the current study should be considered. The lack of diversity in our sample limits the transferability of findings. It is possible that PMC patients of diverse cultural and ethnic backgrounds will follow unique and differing decision-making processes. Moreover, gender and age-related differences might exist. Future work should aim to sample a more diverse group of participants, while considering the contribution of ethnic, racial, gender, and age-related issues as possible influences in treatment decision-making. Next, although study acceptance rates were approximately the same between treatment subsamples, half as many surgery patients were approached for study participation as compared to active surveillance patients. The fact that potential participants were approached at an endocrinology outpatient clinic likely contributed to the disproportion in enrollment by treatment subsample. Future work should aim to recruit patients from surgery clinics. Despite the small sample of surgery participants, the thematic findings from this treatment subsample are still meaningful. Previous research has suggested that meaningful themes can be identified from a sample of six interviews.³⁷ Finally, it is possible that aspects of our methodology impacted participants' responses. Participants may have been more or less likely to focus on certain aspects of their decision-making process when in the company of other cancer patients during focus groups as compared to individual interviews. The fact that we used different moderators for the focus groups and individual interviews and that caregivers were interviewed alongside patients could have facilitated or impeded the discussion in certain ways as well. For example, caregivers may have been less likely to contradict patients, and vice versa. Our sample is too small to definitively rule out such issues. However, these points should be taken into account when considering our findings and conclusions.

Clinical Implications

Our results suggest that PMC patients' decision-making process is greatly influenced by the experience and management of uncertainty. Moreover, surgery and active surveillance appear to offer distinct benefits that are best matched to the unique concerns and focus of different groups of PMC patients. Since a superior treatment is equivocal, it is crucial that physicians remain flexible and responsive to the needs, preferences, and concerns of individual PMC patients. ^{38,39} Physicians must develop an understanding of patients' values, preferences, goals, and beliefs in order to guide clinical recommendations and provide

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information and support. Physicians should also be prepared to discuss the features and potential complications of surgery and active surveillance. Through such steps, physicians can help PMC patients navigate the difficult decision-making process and arrive at a treatment choice that they are comfortable with.

Conclusion

The current study represents the first step in understanding the treatment decision-making process of PMC patients. Our work is timely, given that an increasing number of PMC patients in the United States will be faced with a choice between active surveillance and surgery. Future investigations should expand on this work to develop a more comprehensive understanding of how PMC patients and their caregivers approach initial treatment options and live in the wake of their treatment choice. For example, our preliminary findings concerning the appraisal and management of uncertainty are hypothesis generating. Future work could benefit from exploring such issues using established self-report measures and other quantitative methods. Although caregivers were invited to accompany patients, we asked them to comment and reflect on patients' decision-making process. Future work should focus specifically on the role and unique perspective of caregivers, perhaps interviewing family members and significant others in isolation. We hope that these findings will stimulate work toward the ultimate goal of producing materials to meet the informational needs of PMC patients and to aid in informed decision-making.

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References

- Davies L, Welch HG. Current thyroid cancer trends in the United States. JAMA Otolaryngology-Head & Neck Surgery. 2014; 140(4):317–322. [PubMed: 24557566]
- 2. Enewold L, Zhu K, Ron E, et al. Rising thyroid cancer incidence in the United States by demographic and tumor characteristics, 1980–2005. Cancer Epidemiology, Biomarkers, and Prevention. 2009; 18(3):784–791.
- 3. Hay ID. Management of patients with low-risk papillary thyroid carcinoma. Endocrine Practice. 2007; 13(5):521–533. [PubMed: 17872355]
- 4. Ito Y, Miyauchi A. A therapeutic strategy for incidentally detected papillary microcarcinoma of the thyroid. Nature Clinical Practice: Endocrinology & Metabolism. 2007; 3(3):240–248.
- 5. Ross DS, Tuttle RM. Observing micopapillary thyroid cancers. Thyroid. 2014; 24(1):3–6. [PubMed: 24404786]
- 6. Haugen BR, Alexander EK, Bible KC, et al. 2015 American thyroid association management guidelines for adult patients with thyroid nodules and differentiated thyroid cancer. Thyroid. 2016; 26(1):1–133. [PubMed: 26462967]
- Warlick CA, Allaf ME, Carter HB. Expectant treatment with curative intent in the prostate-specific antigen era: triggers for definitive therapy. Urologic Oncology. 2006; 24(1):51–57. [PubMed: 16414495]
- 8. Ito Y, Miyauchi A, Inoue H, et al. An observational trial for papillary thyroid microcarcinoma in Japanese patients. World Journal of Surgery. 2010; 34(1):28–35. [PubMed: 20020290]

 Oda H, Miyauchi A, Ito Y, et al. Incidences of Unfavorable Events in the Management of Low-Risk Papillary Microcarcinoma of the Thyroid by Active Surveillance Versus Immediate Surgery. Thyroid. 2016; 26(1):150–155. [PubMed: 26426735]

- Brito JP, Ito Y, Miyauchi A, Tuttle RM. A clinical framework to facilitate risk stratification when considering an active surveillance alternative to immediate biopsy and surgery in papillary microcarcinoma. Thyroid. 2016; 26(1):144–149. [PubMed: 26414743]
- 11. Chisholm EJ, Kulinskaya E, Tolley NS. Systematic review and meta-analysis of the adverse effects of thyroidectomy combined with central neck dissection as compared with thyroidectomy alone. The Laryngoscope. 2009; 119(6):1135–1139. [PubMed: 19358241]
- 12. Given B, Wyatt G, Given C, et al. Burden and depression among caregivers of patients with cancer at the end of life. Oncology Nursing Forum. 2004; 31(6):1105–1117. [PubMed: 15547633]
- 13. Given BA, Given CW, Helms E, Stommel M, DeVoss DN. Determinants of family care giver reaction. New and recurrent cancer. Cancer Practice. 1997; 5(1):17–24. [PubMed: 9128492]
- Zeliadt SB, Penson DF, Moinpour CM, et al. Provider and partner interactions in the treatment decision-making process for newly diagnosed localized prostate cancer. BJU International. 2011; 108(6):851–856. [PubMed: 21244609]
- 15. Creswell, JW. Qualitative inquiry & research design: Choosing among five approaches. 2nd. Thousand Oaks, CA: Sage; 2007.
- Green, J., Thorogood, N. Qualitative methods for health research. 2nd. Thousand Oaks, CA: Sage;
 2009.
- 17. ATLAS.ti [computer program]. Vol. 5. Berlin, Germany: Scientific Software Development GmbH; 2016. p. 10Version Version 7
- 18. Glaser, BG., Strauss, AL. The discovery of grounded theory: Strategies for qualitative research. Chicago, IL: Aldine Publishing Company; 1967.
- 19. Lincoln, YS., Guba, EG. Naturalistic inquiry. Thousand Oaks, CA: Sage; 1985.
- Erlandson, DA., Harris, EL., Skipper, BL., Allen, SD. Doing naturalistic inquiry. Newbury Park, CA: Sage; 1993.
- 21. Anandadas CN, Clarke NW, Davidson SE, et al. Early prostate cancer—which treatment do men prefer and why? BJU International. 2011; 107(11):1762–1768. [PubMed: 21083643]
- 22. Chapple A, Ziebland S, Herxheimer A, McPherson A, Shepperd S, Miller R. Is 'watchful waiting' a real choice for men with prostate cancer? A qualitative study. BJU International. 2002; 90(3): 257–264. [PubMed: 12133062]
- Davison BJ, Oliffe JL, Pickles T, Mroz L. Factors influencing men undertaking active surveillance for the management of low-risk prostate cancer. Oncology Nursing Forum. 2009; 36(1):89–96.
 [PubMed: 19136342]
- 24. O'Rourke ME. Narrowing the options: the process of deciding on prostate cancer treatment. Cancer Investigation. 1999; 17(5):349–359. [PubMed: 10370363]
- Xu J, Dailey RK, Eggly S, Neale AV, Schwartz KL. Men's perspectives on selecting their prostate cancer treatment. Journal of the National Medical Association. 2011; 103(6):468–478. [PubMed: 21830629]
- 26. Zeliadt SB, Ramsey SD, Penson DF, et al. Why do men choose one treatment over another?: a review of patient decision making for localized prostate cancer. Cancer. 2006; 106(9):1865–1874. [PubMed: 16568450]
- 27. Kazer MW, Psutka SP, Latini DM, Bailey DE Jr. Psychosocial aspects of active surveillance. Current Opinion in Urology. 2013; 23(3):273–277. [PubMed: 23422588]
- Hedestig O, Sandman PO, Widmark A. Living with untreated localized prostate cancer: a qualitative analysis of patient narratives. Cancer Nursing. 2003; 26(1):55–60. [PubMed: 12556713]
- 29. Litwin MS, Hays RD, Fink A, et al. Quality-of-life outcomes in men treated for localized prostate cancer. JAMA. 1995; 273(2):129–135. [PubMed: 7799493]
- 30. Wallace M. Uncertainty and quality of life of older men who undergo watchful waiting for prostate cancer. Oncology Nursing Forum. 2003; 30(2):303–309. [PubMed: 12692664]

31. Esserman LJ, Thompson IM, Reid B. Overdiagnosis and overtreatment in cancer: An opportunity for improvement. JAMA. 2013; 310(8):797–798. [PubMed: 23896967]

- 32. Vaccarella S, Franceschi S, Bray F, Wild CP, Plummer M, Dal Maso L. Worldwide Thyroid-Cancer Epidemic? The Increasing Impact of Overdiagnosis. The New England Journal of Medicine. 2016; 375(7):614–617. [PubMed: 27532827]
- 33. Welch G. Cancer survivor or victim of overdiagnosis? The New York Times. 2012 Nov.:21.
- 34. Mishel MH. Uncertainty in illness. Image: The Journal of Nursing Scholarship. 1988; 20(4):225–232. [PubMed: 3203947]
- 35. Mishel MH. Reconceptualization of the uncertainty in illness theory. Image: The Journal of Nursing Scholarship. 1990; 22(4):256–262. [PubMed: 2292449]
- 36. Mishel, MH., Clayton, MF. Theories of uncertainty in illness. In: Smith, MJ., Liehr, PR., editors. Middle range theory for nursing. 2nd. New York, NY: Springer; 2003. p. 55-84.
- 37. Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data saturation and variability. Field Method. 2006; 18(1):59–82.
- 38. Epstein, RM., Street, RL. Patient-centered communication in cancer care: Promoting health and reducing suffering. Bethesda, MA: National Cancer Institute; 2007.
- 39. McCormack LA, Treiman K, Rupert D, et al. Measuring patient-centered communication in cancer care: a literature review and the development of a systematic approach. Soc Sci Med. 2011; 72(7): 1085–1095. [PubMed: 21376443]
- 40. Mishel MH. The measurement of uncertainty in illness. Nursing Research. 1981; 30(5):258–263. [PubMed: 6912987]

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Table 1

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Patient demographics

	Active Surveillance (n = 11)	Surgery (n = 4)	Total (n = 15)
Age	mean = 48.4 yrs (SD = 13.2)	mean = 48.3 yrs (SD = 12)	mean = 48.3 yrs (SD = 12.5)
Gender			
Women	90.9%	100%	93.3%
Men	9.1%	0%	6.7%
Race			
White	100%	75%	93.3%
Asian	0%	25%	6.7%
Marital Status			
Married	54.5%	75%	60%
Single	18.2%	0%	13.3%
Living with partner	18.2%	0%	13.3%
Widowed	9.1%	0%	6.7%
Separated	0%	25%	6.7%
Education Level			
High school	27.3%	50%	33.3%
Undergraduate	27.3%	50%	33.3%
Postgraduate	45.5%	0%	33.3%
Occupational Status			
Employed full-time	81.8%	25%	66.7%
Unemployed	9.1%	50%	20%
Employed part-time	9.1%	25%	13.3%
Time Since Diagnosis			
< 6 months	63.6%	75%	66.7%
6 months – 1 year	27.3%	25%	26.7%
> 1 year	9.1%	0%	6.7%

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Table 2

Caregiver demographics

	Active Surveillance (n = 3)	Surgery (n = 3)	Total (n = 6)
Age	mean = 54.7 yrs (SD = 25.1)	mean = 51.7 yrs (SD = 13.5)	mean = 53.2 yrs (SD = 18.1)
Gender			
Men	100%	100%	100%
Race			
White	100%	100%	100%
Marital Status			
Married	66.7%	100%	83.3%
Living with partner	33.3%	0%	16.7%
Education Level			
High school	33.3%	0%	16.7%
Postgraduate	66.7%	100%	83.3%
Occupational Status			
Employed full-time	33.3%	66.7%	50%
Unemployed	33.3%	0%	16.7%
Employed part-time	0%	33.3%	16.7%
Volunteer work	33.3%	0%	16.7%

Table 3

Themes and supporting quotes

Surgery subsample		
Decision to undergo thyroidectomy quickly and with a sense of urgency	"I just knew in my heart 'No, I just want to remove it.' And that was it."	
Perception of PMC as a potentially life-threatening disease	"Cancer is cancer."	
Fear of disease progression and unremitting uncertainty with active surveillance	"Watching could literally be deadly."	
Surgery as a means of control and potential cure	"Every doctor made it sound as if after the surgery that's it. This one's treatable curable. Just take it out and that's it."	
Active surveillance subsample		
View of PMC as a common, indolent, and low-risk disease	"it's the slowest growing. It doesn't spread quicklyit really takes a lot of neglect for it to really get rampant, if at all."	
Concerns about adjusting to life without a thyroid and becoming reliant on hormone replacement medication	"your thyroid is not your tonsils. It's not your appendixit's an important part of your body"	
Openness to reconsidering surgery over the long run	"I have an optimistic attitude about things too and say, well let me see. You can always go for the surgery when things get worse."	
Common themes between subsamples		
Deep level of trust and confidence in physician and cancer center	Surgery: "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 that." Active surveillance: "He sees these things every single dayHe experiments o these things and he would know if it was going to grow fast."	
Use of physician and internet as primary sources of disease and treatment-related information	Surgery: "We relied on Dr. [X] a lot. He definitely calmed me down and he provided a lot of information about thyroid cancer and the surgery." Active surveillance: "Really just Dr. [Y]. He is the one I really trust and so he is the one who told me about everything."	