



A narrative review of decision aids for low-risk thyroid cancer

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Background and Objective: The modern management paradigm underlying low-risk thyroid cancer has evolved considerably across the spectrum of diagnosis, treatment, and surveillance. The indolent nature of most thyroid cancers is increasingly recognized as the primary driver shifting focus to approaches that emphasize quality of life consequences, in contrast to potential overtreatment. Unsurprisingly, controversies persist in areas of treatment equivalence. Management now represents a complex interaction of patient preferences, physician biases, and transparent communication that satisfies stakeholder priorities without violating oncologic principles or standards of care. Shared decision making (SDM) through the use of decision aids is an emerging, potentially valuable means to bridge these factors by individually tailoring extent of surgery based on individual priorities.

Methods: A literature search was performed using PubMed, SCOPUS, and Google Scholar to identify all original articles published in the English language from April 1, 1992 to April 1, 2022 that evaluated tools and aids for decision-making for thyroid cancer patients.

Key Content and Findings: SDM is ideal in situations where the best option is unclear, the decision is sensitive to preference, and the outcome has consequence. In turn, decision aids across disciplines have been shown to reduce decisional conflict, decrease decisional regret, and enhance satisfaction with choices. While decision tools do not consistently change decisions, they do appear to engender more accurate risk perceptions and choices congruent with patient values. For thyroid cancer, conversation aids and question prompt lists currently guide clinic conversations, but no interactive decision aid methodologies exist. The comparative format of conjoint analysis may be most feasible for individualized thyroid cancer decision-making.

Conclusions: Decision aid tools represent an understudied, high-value area of investigation for decision-making in thyroid cancer. Future directions entail incorporating techniques such as conjoint analysis into judicious, effective decision aids tailored to thyroid cancer patients.

Keywords: Thyroid cancer; thyroidectomy; active surveillance; conjoint analysis; decision aids

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Introduction

Across the United States and globally, the incidence of thyroid cancer has more than tripled within the scope of a generation (1). This escalation has been propelled in large part by modern imaging practices that artificially enhance detection of subclinical disease (2). Nearly half a million new cases of thyroid cancer are projected to be diagnosed worldwide in 2020 (3). Based upon autopsy studies that have discovered occult thyroid cancer in up to 36% of cases (4), an even richer subclinical reservoir exists that official statistics fail to capture.

Thyroid cancers exhibit a diversity of behavior, ranging from indolent tumors that are asymptomatic, to aggressive variants that inflict considerable morbidity and death (5). Nonetheless, most cases are considered early stage and curable. Indeed, the 5-year overall survival rate for papillary thyroid cancer (PTC) is outstanding: 97% for all stages and 100% for patients with disease localized to the thyroid (6). As such, health-related quality of life linked to patient preference have taken on greater importance.

For many patients, hemithyroidectomy or total thyroidectomy may be reasonable and equivalent approaches. In some cases, active surveillance represents a third option for microcarcinomas (7). Innovative, minimally invasive transoral approaches as well as radiofrequency ablation techniques have also been introduced. However, the consequences related to these choices vary considerably and may bewilder patients. Physician recommendations, as well as how options are presented, add a further layer of complexity that drive patient choice. Herein, we describe the complexities underlying patient-physician communication, the rationale underlying decision aids, and current efforts to improve shared decision-making for patients undergoing thyroid surgery. We present the following article in accordance with the Narrative Review

reporting checklist (available at <https://aot.amegroups.com/article/view/10.21037/aot-22-9/rc>).

Methods

A literature review was conducted using PubMed, SCOPUS, and Google Scholar to search all English language scientific articles to identify decision aids in thyroid cancer over the past 30 years. Search terms included “thyroid cancer”, “decision aid”, “decision-making”, “thyroidectomy”, or “thyroid surgery”. Original papers were included, while duplicates, review articles, and articles that did not cover decision aids in thyroid cancer were excluded (*Table 1*).

Factors underlying thyroid surgery decision-making

Surgery has remained the standard of care for thyroid cancer for decades. In addition to presumptive survival benefit, thyroidectomy serves to stage malignancy and facilitate administration of radioactive iodine (RAI) when indicated. Advanced thyroid cancers (e.g., tumors >4 cm, metastatic lymph node spread, aggressive subtypes) continue to require multimodality treatment (7). However, for localized cancers, the extent of thyroidectomy is perhaps the most controversial topic in endocrine surgery (8).

Current guidelines endorse hemithyroidectomy or total thyroidectomy for cancers measuring 1 to 4 cm, and hemithyroidectomy or even active surveillance for cancers measuring 1 cm or less (7). For early stage, appropriately selected patients, these options have been shown to confer equivalent long-term survival outcomes. Yet, the majority of patients with low-risk PTC continue to undergo total thyroidectomy, the choice with the greatest potential morbidity (9).

Table 1 Search strategy summary

Items	Specification
Date of search	4/1/2022
Databases and other sources searched	PubMed, SCOPUS, Google Scholar
Search terms used	Thyroid cancer, decision aid, decision-making
Timeframe	4/1/1992–4/1/2022
Inclusion criteria	Original reports, English only
Selection process	Process conducted by primary author Reviewed by co-authors

Such paradoxical findings suggest that when oncologic outcomes (i.e., survival prognosis) are equivalent, attention shifts to qualitative outcomes. For total thyroidectomy patients, this may entail the emotional peace of mind of cancer eradication, even if it means overtreatment (10). For hemithyroidectomy patients, this may entail the desire to avoid taking lifelong thyroid hormone replacement and avoid potential hypoparathyroidism. For active surveillance patients, this may entail the desire to avoid anesthesia, avoid an incision, and avoid even partial removal of a functional organ.

After thyroidectomy, the need for adjuvant RAI treatment also remains controversial. Conflicting data on RAI in reducing recurrence risk and disease-specific mortality has led to considerable uncertainty in management. Current guidelines endorse RAI for intermediate to high risk patients (7), but this is designed to be inclusive and allow clinicians significant latitude on recommending RAI. For patients who decide on treatment certainty with RAI, tradeoffs include potential short-term sequelae (e.g., salivary gland swelling, taste changes, and dry mouth), as well as long-term risks (e.g., nasolacrimal duct obstruction, second primary malignancies, infertility) (11).

Similar gaps in decision-making have been described for other malignancies where the treatment decision is preference-sensitive. Breast cancer patients with higher levels of anxiety are more likely to agree to prophylactic contralateral mastectomy despite the absence of survival benefit (12). Prostate cancer patients with elevated psychosocial distress tend to choose prostatectomy over active surveillance even in the face of complications such as impotence or urinary incontinence (13). The connotation of cancer and the peace of mind conferred by more extreme intervention may outweigh negative consequences, regardless of cancer type.

Shared decision making (SDM)

SDM is the process of actively involving patients in selecting and optimizing screening, treatment and other decisions. SDM respects the patient's ethical right to know and to make autonomous decisions (14). In addition, SDM improves patient satisfaction, reduces post-visit anxiety, and is often associated with the selection of more conservative treatment choices (15,16). SDM is most appropriate in scenarios where a treatment decision needs to be made in which (I) the best option is not clear; (II) the decision has important consequences; and (III) the decision is sensitive

to patient preferences (17). Therefore, SDM is particularly appropriate when considering treatment options for thyroid cancer.

An ideal SDM conversation consists of three phases: (I) choice talk: in this phase the physician explains that there is a choice to make and emphasizes that the patient's preferences should be included in making that choice; (II) option talk: in this phase the patient's pre-existing knowledge is assessed, patient preferences are elicited, and the available options are discussed; and (III) decision talk: in this phase the patient and provider move towards a shared decision and the provider clarifies that choices can be adjusted in the future (18). However, SDM is rare in typical clinical practice. Provider recommendations are discussed extensively, but often little-to-no room is provided for patient preference discussions (19,20). Involvement of family in decisions represents an additional dimension that is often ignored or underestimated, yet which can heavily influence a patient's judgment.

As such, much remains to be studied about the treatment decision-making process for thyroid surgery, especially in a context of treatment equivalence. Such decisions entail a multitude of intangible factors, including trust in the surgeon, patient priorities, life stage, role in family, and past experience. All are incorporated, often in a time-constrained manner, into a single decision that may provoke intense anxiety or psychosocial distress.

The communication between the patient and physician plays a key role in forming a cohesive treatment plan yet in practice is often imperfect. From the patient's perspective, surgeon recommendations and opinion are often the central factor in reaching a decision. Yet, the surgeon may be subject to recall bias and anecdotal fallacy. For instance, clear discrepancies exist regarding the quoted and true impact on sequelae after surgery: patient-reported prevalence of adverse side effects after thyroidectomy in the North American Thyroid Cancer Survivorship Study were far higher than the rates estimated by physicians (21). This includes "change in singing or everyday speaking voice" (54.9% vs. 5.0%), "dry mouth symptoms" (61.9% vs. 1.0%), and low calcium requiring medication for more than 2 months" (31.6% vs. 1.0%). Such variance highlights the important gaps and information asymmetry faced by patients when considering treatment options.

From the surgeon's perspective, the impression of a patient's anxiety and risk tolerance often shape their recommendations. However, physicians have often reported being ill-equipped to elicit and incorporate patient

preferences (22). Assumptions often lead to emotional forecasting of patient preferences, which can be heavily influenced by biased values and paternalistic beliefs. Concurrently, the majority of patients have also reported not being asked about preferred goals, and are often offered just one treatment option (23).

Deeper understanding of self-reported priorities will better inform patients as well as the physicians who counsel them. Doubleday *et al.* concluded from their analyses that both parties favor SDM, with the patient controlling the final decision (23). The use of tools to build upon SDM may bridge communication gaps and simplify the complexities encountered by thyroid cancer patients.

Decision aids

Decision aids are tools that can be used by patients, healthcare professionals, or both to facilitate the shared-decision making process. A decision aid includes information that can assist the patient in decision between the different treatment options available. This information can be presented in a static format, using video, or in an interactive design. Some tools are developed for use in a doctor's office, while others are used by patients to prepare for their visit (24). Decision aid interventions have been demonstrated to reduce decisional conflict, improve SDM, and enhance satisfaction with choices (25-27).

The International Patient Decision Aids Standards (IPDAS) has developed a set of quality criteria for the development of decision aids (24). Robust decision aids include sufficient detail about the available treatment options, including an overview of the pros and cons of each option. Data about the probability of desired and undesired outcomes should be presented in an unbiased way, that allows patients to adequately compare benefits and risks. In addition, worthwhile decision aids include methods to help patients clarify their values and preferences, and include guidance on the decision-making process (24). To develop an effective decision aid, a systematic development process should be used with the involvement of end-users to ensure usability and understandability (24,28).

To help patients clarify their preferences, a variety of methodologies can be used. These methods include an open discussion in which patients openly talk about the benefits and risks of various options, forms on which patients rate or rank various options, or interactive methods such as conjoint analysis or time trade-off (TTO) methods (29). In TTO exercises, patients are asked to iteratively trade-off life

years against treatment benefits and harms (30). Conjoint analysis on the other hand encompasses a series of rating exercises in which patients decide amongst competing treatment attributes (31,32).

The most appropriate choice likely depends on the scenario. TTO for example might be the most appropriate methodology when tradeoffs have to be made between life expectancy and quality of life, common to many oncologic scenarios (33). However, as the alternatives typically include death, this method might not be appropriate in diseases with low disease-related mortality (34). In these cases, conjoint analysis might be more appropriate alternative as it allows patients to compare treatment options side-by-side, which may appear less threatening (35). In addition, conjoint analysis tasks are perceived to be easier than TTO tasks, thereby allowing the use of remote administration rather than administration through an interview process. Such advantages make conjoint analysis more feasible within the context of a clinical practice (36).

The use of decision aids as interventions has had measurable impact on patients facing treatment or screening decisions across the healthcare landscape. A Cochrane database review of 105 randomized control trials examining decision tools for a spectrum of decisions (i.e., surgery, cancer screening, genetic testing, drug treatments) found that they conferred consistent benefit compared to usual care (25). This included increased patient knowledge, enhanced accuracy of risk perception, and value-care congruency. Decision tools also diminished decisional conflict, reduced the percentage of undecided patients, and improved patient-clinician communication. Interestingly, decision tools also reduced the likelihood of choosing major elective invasive surgery in comparison to more minimalist options. It is also noteworthy that the use of decision tools was not time-intensive: they increased the length of the clinic visit by just a median of 2.6 minutes. Altogether, decision aids appear to ensure patients are better informed and more engaged, which in turn leads to more accurate risk perceptions and value-congruent choices.

Progress in thyroid cancer decision aids

For thyroid cancer, less research has been conducted in relation to decision aids. To some degree, this may be due to the more straightforward nature of thyroidectomy. The surgery can be conducted as a relatively short outpatient procedure, complication rates are low, and resection is typically definitive. Surveillance after surgery, in contrast to

Table 2 Thyroid cancer decision aids in the literature at different decision points of management

Decision aid	Methodology	Decision point	Study type	Key benefits
Thyroid Nodule Conversation Aid (45)	Human-centered design	Thyroid nodule management	Feasibility study (n=65)	Increased patient involvement
	Conversation aid			Increased clinician satisfaction Decreased decisional conflict
Thyroid Cancer Treatment Choice (46)	Evidence-based information materials for patients	Surgery options for microPTC	Pilot study (n=278)	Promoted more balanced presentation of treatment options
	Question prompt list			Increased acceptance of active surveillance
Treatment Comparison Chart Question Prompt List (47)	Iterative process outlined by International Patient Decision Aids Standards	Surgery options for low-risk thyroid cancer	N/A	Improved medical knowledge
	Informed by patient advisory board and clinician advisory board			Increased patient involvement
Computerized Decision Aid (6)	Evidence-based development	RAI options after thyroidectomy for early stage PTC	Randomized control trial (n=74)	Improved medical knowledge
	Informed by multidisciplinary physicians and patient focus group			Reduced decisional conflict No change in RAI use compared to usual care control

PTC, papillary thyroid cancer; N/A, not available; RAI, radioactive iodine.

active surveillance, is less cumbersome. In contrast, other low-risk cancers may entail issues of higher complexity. Breast cancer decision-making may involve genetic implications of prophylactic mastectomy, potentially higher emotional stakes from perceptions of body dysmorphia, and extended surgical reconstruction. Prostate cancer decision-making evokes consideration of more impactful complications, as well as the interplay from shorter life expectancy on an older patient demographic.

However, a number of thyroid-centric studies have begun to explore communication, physician perspectives, patient worry, and emotion as drivers of decision-making (37-44). These qualitative factors have been shown to be bimodal in purpose: they may function as heuristic shortcuts, or they may serve to better calibrate accurate risk perception.

More tangibly, conversation aids have been created for different timepoints in thyroid cancer management (Table 2), including biopsy, surgical decision making, and need for adjuvant therapy. Such tools have taken different approaches to help strengthen gaps in patient care:

- ❖ Ospina *et al.* developed a Thyroid Nodule Conversation Aid (TNOC) via a human-centered design (45). In a feasibility study of 65 patients with thyroid nodules, TNOC was associated with

increased patient involvement, increased clinician satisfaction, and decreased decisional conflict.

- ❖ Brito *et al.* developed Thyroid Cancer Treatment Choice (TCTN) via an iterative process based on the principles of interaction, design, and participatory action research (46). Pilot testing the conversation aid with 278 patients with microPTC in Korea demonstrated that the aid promoted a more balanced presentation of treatment options, and in fact increased acceptance for active surveillance in the conversation aid group compared to the usual care group. Such findings are intriguing because they suggest that decision tools thoughtfully incorporated into clinics may change management, rather than simply better inform patients.
- ❖ Pitt and Saucke used IPDAS methodology in conjunction with key stakeholders (patient family advisory board, clinician advisory board) to create two complementary decision support aids for low-risk thyroid cancer patients (47). A treatment comparison chart considered multiple domains such as treatment, guideline recommendations, outcomes, and quality of life. A question prompt

list considered issues that patients may want to ask their physician, explicitly covering topics such as treatment options, outcomes, complications, surgeon volume, and unanticipated issues. Such interventions were designed to enhance patient-physician communication, empower patients, and calibrate information (or misinformation) found online.

- ❖ Sawka *et al.* developed a computerized decision aid to assess decision-making for RAI after thyroidectomy for early-stage PTC (6). The decision aid was based upon thyroid cancer survivor focus groups, systematic reviews of the literature, and usability testing by stakeholders including physicians and patients. In a randomized controlled trial of 74 thyroidectomy patients, the decision tool improved medical knowledge and reduced decisional conflict compared to usual care, but did not change the use of adjuvant RAI.

Conclusions

In summary, the factors that underlie treatment decisions in thyroid cancer entail high complexity and have potential to create psychosocial distress. Promotion of value congruent care, SDM that acknowledges patient preferences and surgeon expertise may best optimize choice of surgery extent and RAI administration. Decision tools may best translate this into practice, with initial studies showing great promise in delivering practical gains for patient and physician. Further decision aid work should focus on robust methodology to individualize the functional, oncologic, and prognostic tradeoffs between different approaches for thyroid cancer, and to quantify the level of worry that may drive patient decisions. The convergence of these priorities may best optimize outcomes in the modern era of patient-centered care.

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