# **PAPER**

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Thyroid cancer patients receiving an interdisciplinary teambased care approach (ITCA-ThyCa) appear to display better outcomes: Program evaluation results indicating a need for further integrated care and support

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# **Abstract**

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Background: Thyroid cancer (ThyCa) is generally associated with a favorable prognosis and excellent surgical outcomes. Consequently, its treatment is medically focused and current guidelines recommend interdisciplinary care including access to a nurse for complex cases alone. To date, no studies have evaluated the need for and impact of an Interdisciplinary Team-based Care Approach (ITCA-ThyCa) for general thyroid cancer patients, including a dedicated nurse as part of a larger interdisciplinary team, as well as patient-reported outcomes, as is recommended worldwide in cancer care. Our aim was to evaluate such a program.

Methods: The ITCA-ThyCa was evaluated within a quasi-experimental design using the Centers for Disease Control Framework for Program Evaluation, including process and outcome measures. Patients eligible were adults with a biopsy indicating confirmed or highly suspicious ThyCa (TNM-Classification + Bethesda score of V/VI). The intervention group (IG) received ITCA-ThyCa and the comparison group (CG), usual care alone.

Results: In our sample comprised of 200 participants (122 IG; 78 CG), ITCA-ThyCa patients appeared to show significantly better outcomes than CG patients, namely, higher levels of overall well-being (P = .001) and fewer physical (P = .003) and practical (P = .003) issues and concerns. More satisfied with their overall care (P = .028), including care coordination (P = .049), they reported their health care provider as more approachable (P = .007), respectful (P = .005), and

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trustworthy (P = .077; trend) and were more likely to recommend their hospital (P = .02). Ninety-eight percent of IG patients recommended ITCA-ThyCa.

**Conclusion:** Data from our program illustrates that hospital resources should not be allocated based on medical trajectory alone and challenges the idea that ThyCa is "straightforward." ThyCa patients seem to experience symptom distress at a level comparable to—or exceeding—that of general oncological patients despite their promising medical outcomes, indicating that better integrated care and support are in order.

#### **KEYWORDS**

anxiety, cancer, clinical guidelines, interdisciplinary care, oncology, screening for distress, symptom management, thyroid cancer

# 1 | INTRODUCTION

Thyroid cancer (ThyCa) is typically diagnosed in early stage and associated with a good medical prognosis, with survival depending on cancer cell type and disease staging. Treatment usually involves surgery, ie, hemithyroidectomy or total thyroidectomy with or without neck dissection, levothyroxine thyroid hormone replacement therapy, radioactive iodine treatment (I-131) as required, and long-term surveillance and monitoring through routine physical exams and thyroglobulin tests. Patient care has traditionally followed a strictly medical model, including surgery, endocrinology, and nuclear medicine, largely attributable to the medically straightforward trajectory of the disease and favorable treatment outcomes. While guidelines recommend interdisciplinary care in complex medical cases (eg, metastatic nodes >8 to 10 mm; metastases nonresponsive to I-131; bone metastases), the focus is again uniquely medical, solely emphasizing diagnosis and management.<sup>1</sup>

Given its excellent prognosis, the tendency is to compare ThyCa outcomes with the general population rather than a usual oncologic comparison.<sup>2</sup> A recent systematic review<sup>2</sup> reports surgery as negatively impacting short-term quality of life (QoL) (eg, vitality/fatigue, physical functioning, role physical, bodily pain, general health, role emotional, and mental health), with levels resuming to preoperative as time evolves since surgery. Quality of life becomes compromised following adjustments to levothyroxine hormone replacement therapy (leading to hypothyroidism or hyperthyroidism), and thyroid hormone withdrawal required pre-I-131 or follow-up scans unless followed by a recombinant human thyroid stimulating hormone injection.<sup>2</sup> Findings are contradictory for longer-term QoL impairment, either highlighting persistent health problems and lowered QoL or resuming baseline. A study of 518 ThyCa survivors<sup>3</sup> identified two-thirds (64.5%) as experiencing persistent symptoms, especially neurologic, musculoskeletal, and psychological, with long-term symptoms of thyroid hormone imbalance in 25% including chronic fatigue. Other studies<sup>4</sup> have found common long-term QoL impairments in vitality/ fatigue, mental health, and social functioning. It is not uncommon for studies to emphasize the stressful nature of ThyCa and need to improve their care using a broader interdisciplinary care model,<sup>5</sup> akin to the current standard of care in oncology.<sup>6,7</sup> While the impact of interdisciplinary care has been studied in other medical populations including in oncology, with positive effects on levels of QoL, physical symptoms. anxiety, and depression, 8-12 no study has investigated its impact on ThyCa patients (ThyCa-P) and the need remains unmeasured.

This study aimed to implement and evaluate the need for and impact of an Interdisciplinary Team-based Care Approach for thyroid cancer patients (ITCA-ThyCa).<sup>13</sup> This care comprised a collaborative care model,<sup>14</sup> including a dedicated nurse within a broader interdisciplinary team (as described below), and patient-reported outcomes, as recommended worldwide in cancer care,<sup>6,7</sup> with 3 supportive care meetings planned according to medical treatment and previously identified health care gaps and needs.<sup>5</sup> We hypothesized that patients receiving ITCA-ThyCa (Intervention Group; IG) would demonstrate 1 month postsurgery higher overall well-being, lower anxiety and fatigue, and higher satisfaction with care compared to a comparison group (CG).

#### 2 | METHODS

### 2.1 | Study design

A quasi-experimental design was used to evaluate ITCA-ThyCa based on the CDC (2014) Framework for Program Evaluation, 15 comprising both process and outcome evaluation, and including clinical practice guidelines for distress-screening.<sup>6,7</sup> All Jewish General Hospital (JGH) ThyCa-P received ITCA-ThyCa in addition to usual care. Usual care as it stood preimplementation consisted of strictly physician-based care (ie, surgeons, endocrinologists, and nuclear medicine) without a dedicated nurse and broader interdisciplinary team (ie, including dietetics, pharmacy, social work, psychology, and volunteer community supports). The external CG comprised of patients having undergone a hemithyroidectomy or total thyroidectomy <1 year at the McGill University Health Center (MUHC; Royal Victoria Hospital and Montreal General Hospital sites), a center with similar sociodemographic and clinical profiles, as well as medical approach (ie, ATA Guidelines). Comparison group patients completed Edmonton Symptom Assessment Scale (ESAS) at one time point within the year postsurgery as they refused to complete measures presurgery.

Process evaluation was defined as degree of program implementation as designed, including measures of activities and outputs. <sup>15</sup> Outcome evaluation meant degree of impact on selected outcomes, <sup>15</sup> as evidenced by scores on clinical measures, satisfaction, and interviews. Distress-screening using the Edmonton Symptom Assessment System (ESAS) was integrated, administered at the onset of each nurse meeting to guide her treatment approach and track clinical change over

time. Process and outcome indicators are further described below. Ethics approval was obtained by the Institutional Review Boards of all hospitals involved (IRB no. 13-063), with participants consenting postsurgery to using their data.

It became apparent in the first 6 months of recruitment that randomization was unfeasible as patients were too distressed to consent into a study during waiting times for surgery. We could not consent precancer diagnosis without a strong ethical rationale to conceal study purpose, and consenting postdiagnosis meant missing the opportunity of introducing the nurse in-hospital during patients' sole medical appointment presurgery. Patients accepted the program evaluation design since it was integrated into routine clinical care, precluding investing additional time.

# 2.2 | Population

Participants in the IG (1) had a recent biopsy indicating confirmed or highly suspicious ThyCa (TNM-Classification<sup>16</sup> + Bethesda score of V/VI<sup>17</sup>) and were awaiting treatment at the JGH and (2) were ≥18 years. The same inclusion criteria were retained for the CG except they had undergone a hemithyroidectomy or total thyroidectomy ≤1 year at the MUHC. There were no exclusion criteria.

The ITCA-ThyCa was developed and manualized in collaboration with the Jewish General Hospital Departments of Otolaryngology-Head and Neck Surgery, Psychology, and Nursing. 13 It comprised of a collaborative care model<sup>14</sup> including 4 components: a multiprofessional approach to patient care, a structured management plan, scheduled patient follow-ups, and enhanced inter-professional communication. The team included surgery, endocrinology, nuclear medicine, nursing, dietetics, pharmacy, social work, psychology, and volunteer-based community supports. The nurse navigator had a central, integrative role, including distress-screening using ESAS<sup>7,18-20</sup> before each meeting and further evaluation/intervention on clinically significant symptoms (ESAS  $\geq$  4, PHQ-9&GAD-7  $\geq$  10<sup>21</sup>) using a strengths-based nursing care model<sup>22</sup> and family assessment and intervention model<sup>23</sup> as well as clinical practice guidelines<sup>6,7</sup>; service coordination and continuity of care from diagnosis onwards; information provision about the illness, its treatments, cancer- and treatment-related symptom management; provision of emotional support; communication of patients' issues and concerns within the interdisciplinary team; and liaison/referral to relevant hospital- and community-based resources as needed.<sup>6,7</sup> The nurse was integrated into the monthly previously strictly medical, physician-based, team meetings, with the goal of reviewing cases from a biopsychosocial perspective (ie, cases presenting challenging physical, psychological, or social issues) and developing, discussing, and implementing comprehensive integrated treatment plans in collaboration with larger interdisciplinary team members.

The nurse was systematically present when physicians informed patients of their biopsy results and presented their treatment plan. She scheduled 3 information/support meetings with patients in-hospital, or via telephone or internet, and planned according to medical trajectory and known ThyCa information needs (1) immediately upon receiving biopsy results indicating confirmed or highly suspected ThyCa (presurgery) (theme: ThyCa, emotional impact, treatment plan/short- and long-term impact, ATA Statement on essential perioperative information<sup>24</sup>); (2) 1 month postsurgery (pre-I-131) (theme: I-131,

associated safety precautions and diet); and (3) during the first endocrinology follow-up visit (theme: fear of recurrence, using the diagnosis as a wake-up call to live meaningfully). For rare patients receiving chemotherapy and/or radiation therapy instead of surgery, the nursing meetings were planned (1) upon biopsy results; (2) upon treatment onset; (3) during treatment; and (4) upon treatment completion (anaplastic cancer #1-3 only). Meeting content and length depended on distress-screening results, patients' needs, and preferences for information/support and the treatment plan. The nurse was available as needed for support in-between meetings, and weekly availabilities were planned in her schedule to handle drop-ins. She charted dates and duration of all meetings, scheduled and unscheduled, as well as evaluations, interventions, referrals, and interdisciplinary team discussions (within and outside of the team meeting) with the resulting treatment plan. She met weekly with the psychologist and research team to discuss implementation challenges and clinical cases.

#### 2.3 | Usual care

The JGH and MUHC both represent large McGill University-affiliated hospitals using ATA Clinical Guidelines. Typically, patients met a surgeon, underwent a biopsy, then surgery requiring one-night (median) hospitalization, followed-up post discharge for suture removal and final pathology results, received I-131 as indicated medically, and were seen every 6 to 12 months in endocrinology. Prior to this study, strictly medical physician-based meetings were held monthly to discuss clinical case management. Neither hospital had previously offered ThyCa-P access to a broader interdisciplinary team including a dedicated nurse and other allied professionals.

#### 2.4 | Outcome evaluation

The primary research question was, "Does adding the ITCA-ThyCa (Intervention Group (IG)) to usual care (ie, ATA Guidelines<sup>1</sup>) increase levels of overall well-being at 1 month postsurgery among newly diagnosed ThyCa-P, compared with the levels found in patients having received usual care alone (Comparison Group or CG)?" *Primary hypothesis*: The IG will report higher scores of ESAS overall well-being 1 month postsurgery than the CG.

The secondary research questions were, "Does adding ITCA-ThyCa (IG) to usual care decrease levels of anxiety and fatigue as well as increase levels of satisfaction with care at 1 month postsurgery? *Hypotheses*: The IG will report a lower level of anxiety and fatigue on the ESAS and higher levels of satisfaction with care compared to the CG at 1 month postsurgery. We chose anxiety and fatigue as secondary outcomes since they were frequently reported in ThyCa. <sup>2,3</sup> We also planned to explore intergroup differences on the Canadian problem checklist (CPC) domains (see below description).

# 2.5 | Process evaluation

We used the following indicators, as suggested in the guidelines for distress management<sup>6,7</sup>: *Screening and Early Identification of Distress*–90% underwent distress-screening. *Teamwork and Collaboration*–90% scores  $\geq$  4 further assessed and referred as needed +90% of cases with score  $\geq$  4 discussed by the interdisciplinary team and integrated care is

developed based on evidence-based practices.<sup>6,7</sup> Patient Satisfaction—90% recommend ITCA-ThyCa to all.

#### 2.6 | Outcome measures

The IG and CG patients completed the English- and French-validated ESAS, CPC, and satisfaction with care questionnaire (SCQ). Intervention group patients completed the client program satisfaction questionnaire (CPSQ), patient health questionnaire-9 (PHQ-9), and general anxiety disorder-7 (GAD-7).

The ESAS is a distress-screening tool routinely used in cancer care  $^{7,25,26}$  with 9 common symptoms rated on a 0 to 10 numerical scale combined in a total scale  $^{26}$ : pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath (internal consistency— $\alpha$  = .79-93; test-retest reliability—r > .80). $^{26}$  The CPC $^{7}$  is recommended for use in combination with ESAS and screens for 21 common problems in 4 domains: emotional, practical, physical, and spiritual concerns.

The PHQ- $9^{22}$  measures DSM major depressive disorder symptoms (internal consistency— $\alpha$  = 0.89; test-retest reliability—r = 0.84) and the GAD- $7^{22}$  measures DSM-GAD symptoms (internal consistency— $\alpha$  = 0.92; test-retest reliability—r = 0.83). Scale cut-offs: 5 = mild; 10 = moderate; 15 = moderately severe; and 20 = severe.

The *SCQ* comprised 10 questions inspired by the Picker Patient Experience Questionnaire, <sup>27</sup> including the following themes: trust in healthcare providers (HCP), feeling respected by HCP, feeling HCP addressed one's concerns, healthcare team coordination, HCP knowledge, HCP-patient communication, intra-health care team communication, and recommendation of treating hospital to others. The *CPSQ*, based on the client satisfaction questionnaire, <sup>28</sup> included 11 response-option/open-ended questions to assess ITCA-ThyCa satisfaction, including general experience, most helpful/difficult components, improvement suggestions, perception of nursing as essential, and recommendation of the program.

Interdisciplinary exchanges (ie, face-to-face or telephone communication about the patient, involving the nurse and interdisciplinary team member) and referrals for ITCA-ThyCa-P were tracked at each evaluation time-point through chart review (ie, date/source of exchange/referral, type of professional, referral reason).

# 2.7 | Patient interviews

A psychologist experienced in interviews/ENT (MH) and a medical student (YXC), presented as such to participants, conducted individual interviews to better understand ITCA-ThyCa experience. A purposive sample of 17 patients (based on data saturation<sup>29</sup>), with no prior relationship to the interviewers, were selected using maximum variability on axes of gender, ThyCa type, distress level, and planned treatment (total thyroidectomy vs hemithyroidectomy, I-131). Interviews were conducted using descriptive phenomenology and respected criteria for methodological rigor (credibility, transferability, dependability, and confirmability).<sup>29</sup> As described to participants, the interviews strove to obtain a rich and in-depth description of experience of the program and more specifically of meetings with the nurse. As such, an interview guide was used with prompts to help patients elaborate their

narratives, field notes were made postinterviews, and the data were fed-back to participants in later interviews for their input.

# 2.8 | Data analysis

First, we ran descriptive statistics to characterize our sample sociodemographically and medically, as well as to identify most pressing areas of needs on ESAS and CPC. Second, we identified intergroup differences on outcomes (IG vs CG) using independent-sample *t* tests for continuous variables (primary outcome: level of general well-being; secondary outcomes: fatigue, anxiety, and satisfaction with care; exploratory outcomes: CPC domains). Third, we adjusted analyses for between-group differences on sociodemographic/medical variables using ANCOVA. Fourth, we identified symptom change over time (preoperative vs postoperative) using dependent-sample *t* tests and chi-square. Finally, interviews were audio-recorded, transcribed verbatim, and analysed using content analysis<sup>29</sup> with N\*Vivo version 11. Transcripts were read and excerpts coded in nodes, modified as analyses evolved with each step saved (ie, audit trail).

# 3 | RESULTS

### 3.1 | Sample

One hundred and seventeen patients participated in ITCA-ThyCa, with no patient refusing the program. Seventy-eight (50% of 156) participated in the CG. Comparison group responders and nonresponders (on gender, age, surgical procedure, and language; P = .35-.58), as well as IG and CG patients were similar sociodemographically and medically (see Table 1).

# 3.2 | ITCA-ThyCa nursing interventions and interdisciplinary care

One-hundred and seventeen patients underwent distress-screening (96%), with a total of 252 screens (mean: 2.07 per patient (pp); SD: 1.19; range: 0-5); 26.6% (n = 67) had at least one symptom at severe distress level and 67.9% (n = 172) in moderate range. The nurse conducted a total of 586 patient meetings (mean: 4.9; median: 3; range: 1-54 pp). She clinically assessed all ESAS scores ≥4 and referred 80% of patients (n = 160 referrals; mean:1.3 pp; range: 0-7), including to Hope&Cope/Wellness Center Montreal (n = 83; 70.9%), psychologist (n = 30; 25.6%), physiotherapist (n = 11; 9.4%), social worker (n = 6; 5.1%), palliative care (n = 4; 3.4%), speech and language therapist/dietician (n = 4; 3.4%), psychiatrist (n = 2; 1.7%), fertility clinic (n = 1; 0.9%), cancer nutrition-rehabilitation program (n = 1; 0.9%), memory clinic (n = 1; 0.9%), other community resources (GP, nurse, association for young adults with cancer) (n = 12; 10.3%). The interdisciplinary team conducted case discussions on 94%, and there were 420 interdisciplinary exchanges (mean: 3.4 pp; median: 2; range: 0-85).

Of 51.6% presenting with anxiety  $\geq$  4, 88.2% received at least one targeted intervention (mean: 2.0 pp; SD: 0.8; range: 1-4), and the other 11.8% were already receiving professional support. Most frequent nursing interventions included active listening (38.2%), answering patients' concerns/questions (29.1%), referral to psychologist (14.5%; 5.5% already had, 3.6% refused), and exploring/reinforcing patients'

**TABLE 1** Intergroup differences sociodemographically and medically

Sociodemogr variable	aphic / medical	IG n(%)/ x(SD)	CG n(%)/ x(SD)	P Value
Gender	Female	91 (74.6)	60 (76.9)	.71
Age		50.2 (17.1)	51.8 (15.1)	.49
Marital status	Married/common- law	63 (63.3)	52 (66.7)	.10
	Divorced/separated Single Widowed	2 (2.0) 28 (27.7) 8 (7.9)	7 (9.0) 14 (17.9) 5 (6.4)	
Education	Elementary High-school CEGEP/vocational University— undergraduate	0 (0) 13 (21.7) 15 (25.0) 16 (26.7)	19 (24.7) 24 (31.2)	.58
	University—graduate	16 (26.7)	21 (27.3)	
Ethnicity	North-American European Asian Other	22 (37.3) 13 (22.0) 8 (13.6) 16 (27.1)		.18
Language	English French	35 (58.3) 25 (41.7)	37 (47.4) 41 (52.6)	.20
Cancer	Papillary/follicular Medullary/anaplastic Other	106 (88.4) 8 (6.7) 6 (5.0)	48 (100) 0 (0) 0 (0)	.06†
Surgery	Total thyroidectomy Hemithyroidectomy	79 (85.9) 13 (11.1)	48 (63.2) 26 (36.8)	.02*
Time since surgery (days)		112.1 (10.1)	139.4 (15.8)	.001**
Neck dissection		35 (29.9)	28 (35.2)	.13
I-131		41 (36.0)	27 (38.6)	.60

Abbreviations: CG, comparison group; IG, intervention group.  $^*p < .05$ ;  $^{**}p < .01$ ;  $^{\dagger}$ trend.

current coping/support (14.5%). Of 60.7% presenting with tiredness  $\geq$  4, 78.3% received at least one targeted intervention (the rest felt no need) (mean: 1.1 pp; SD: 1.0; range: 1-4), including sleep hygiene (60%), fatigue management pamphlet (15.5%) or website (6.9%), and work on energy conservation/management of activities and life-roles (6.9%). All 10 patients reporting depression  $\geq$  4 (15.6%) were referred to psychology.

# 3.3 | Intergroup differences on outcomes

Compared to CG patients, IG patients showed significantly higher levels of (ESAS) overall well-being (P = .001), lower tiredness (P = .047), and fewer problems with physical (P = .003) (ie, weight/concentration/sleep), spiritual (P = .002) (ie, faith/meaning in life), practical (P = .032) (ie, work/school, finances, getting to/from appointment, and accommodation), and social/family (P = .088; trend) CPC dimensions. As an exploratory observation departing from original hypotheses, IG patients had fewer problems with appetite (P = .004) and shortness of breath (P = .01) (see Table 2). In analyses adjusted for significant inter-group differences (ie, surgery type and time since surgery), IG patients still presented significantly higher overall well-being (P = .004), as well as lower tiredness (P = .08; trend), pain (P = .049), drowsiness (P = .048), shortness of breath (P = .003), problems with appetite (P = .002), and physical (P = .05) and spiritual concerns (P = .09; trend). When ThyCa type was added as confound, these differences remained except in nausea where groups showed equivalent (P = .85).

# 3.4 | Satisfaction with care and need for a dedicated nurse

Intervention group patients had significantly higher satisfaction scores (SCQ) than CG patients (P = .02). They reported feeling more capable of approaching their HCP with questions/concerns (P = .007), that their HCP treated them more respectfully (P = .004), more satisfied with care coordination (P = .04), more likely to recommend their HCP (P = .02), more satisfied with their care (P = .07; trend), and trusting their HCP more (P = .07; trend) (see Table 2). Of 80 IG patients completing CPSQ, 89% positively benefited from access to a nurse and 98% recommended it for all.

Most important needs for ITCA-ThyCa patients preoperatively included anxiety (43%), tiredness (42%), well-being (20%), depression (17%), and pain (17%). Postoperatively, these issues diminished in intensity: well-being (30%) (P = .05;trend), anxiety (23%) (P = .003), appetite (23%) (P = .002), and drowsiness (21%) (P = .005); whereas depression (17%) and tiredness (50%) stayed similar (P = .66 and .40, respectively).

Preoperatively, most frequently endorsed CPC dimensions included emotional (43.3%), physical (30.9%), social/family (24.7%), informational (23.7%), practical (22.7%), and spiritual (5.1%) domains. These problems persisted postoperatively (P > .05), with physical (48%) and emotional (45%) domains remaining most important (see Table 3).

# 3.5 | ITCA-ThyCa patient interviews

Of the 27 patients contacted for interviews, 17 (70.8%) accepted participation. Sixteen interviews (94.1%) were conducted face-to-face at the hospital, and one was conducted via telephone (median duration: 53 min; range: 38-69). Patients reported several benefits to having a nurse (see Table 4): (1) provision of (rapid) support and information (ie, reviewed information postdiagnosis and addressed questions as time progressed, perceived the nurse as available) (Quote #1), (2) symptom management (eg, helped with managing fatigue, pain, anxiety) (Quote #2), (3) reassurance/continuity of care (ie, provided guidance and stability) (Quotes #3), (4) timely interdisciplinary referrals (ie, served as liaison between patients and other team members) (Quote #4), (5) attenuation of patient's psychological distress (ie, patients felt less anxious/preoccupied) (Quote #5), (6) companionship during the entire process (ie, provided continuous support, showed genuine interest in the patient's overall well-being, and focused on more than "just the physical health of the patient") (Quote#6), (7) encouraging patients' healthy attitude (ie, encouraged making positive behavior changes) (Quote#7), and (8) normalizing the cancer experience (ie, normalized reactions, allowing for more openness and self-awareness) (Quote #8). All found the nurse essential and important to continue funding ITCA-ThyCa.

#### 4 | DISCUSSION

This study contributes to the scientific literature in several ways. First, it underlines for the first time the need for and potentially positive impact of interdisciplinary care on outcomes in ThyCa-P using a

TABLE 2 Intergroup difference postsurgery—ESAS, CPC, and SCQ

Outcomes	IG Mean (SD)	CG Mean (SD)	P Value <sup>c</sup>
ESAS			
General well-being <sup>a</sup>	2.7 (2.5)	4.1 (2.7)	.001**
Tiredness <sup>b</sup>	3.6 (2.9)	4.5 (2.9)	.047*
Anxious <sup>b</sup>	2.4 (2.8)	2.8 (2.9)	.45
Depressed	1.5 (2.3)	1.6 (2.4)	.85
Pain	1.3 (2.2)	1.9 (2.6)	.13
Nausea	0.9 (2.0)	0.9 (1.8)	.98
Drowsy	1.9 (2.6)	2.8 (3.1)	.06 <sup>†</sup>
Appetite	1.9 (2.8)	3.4 (3.2)	.004**
• •			
Shortness of breath	1.5 (2.1)	2.7 (3.0)	.011*
Total score CPC	17.8 (15.7)	24.5 (16.1)	.01*
Physical	0.8 (1.0)	1.3 (1.0)	.003**
Emotional	0.9 (1.2)		.14
Practical	0.4 (0.7)	1.3 (1.4) 0.7 (0.9)	.03*
Informational	0.4 (0.7)	0.7 (0.9)	.03
			.02*
Spiritual Social-family	0.2 (0.5)	0.4 (0.6) 0.7 (0.9)	.02 .08 <sup>†</sup>
CSQ CSQ	0.5 (0.7)	0.7 (0.9)	.00'
HCP addressed concerns/issues	6.4 (1.0)	6.1 (1.2)	.16
Able to approach HCP with concerns	6.4 (0.9)	5.8 (1.7)	.007**
Trusts HCP	6.6 (0.7)	6.3 (1.3)	.07 <sup>†</sup>
HCP treats me respectfully	6.7 (0.7)	6.2 (1.4)	.004**
HCP knew my medical dossier	6.4 (0.9)	6.1 (1.3)	.20
Satisfaction with care coordination	6.2 (1.1)	5.8 (1.4)	.044*
Satisfaction with inter-team communication	6.1 (1.3)	5.8 (1.5)	.16
Satisfaction with care	6.5 (0.8)	6.1 (1.3)	.07 <sup>†</sup>
Would recommend HCP	6.7 (0.8)	6.3 (1.2)	.02*
Total Score <sup>b</sup>	58.0 (6.4)	54.6 (10.5)	.02*
Nurse access essential?	3.3 (1.0)	3.4 (0.9)	.61
Recommend nurse access?	73 (97.3%)	66 (97.1%)	.92

Abbreviations: ESAS, Edmonton Symptom Assessment System; CPC, Canadian Problem Checklist; CSQ, Client Satisfaction Questionnaire; IG, intervention group; CG, comparison group.

longitudinal design and program implementation approach. Adding ITCA-ThyCa to usual standards of care (ie, ATA Guidelines) seems to have resulted in higher levels of overall well-being as well as alleviated physical symptoms. Second, ITCA-ThyCa patients considered access to a nurse as essential and recommended it as an important component of care. Because of the nurse, patients described their concerns as being addressed early, in a timely manner, and effectively, through information provision, symptom management, and referrals to appropriate hospital and/or community services. Third, ITCA-ThyCa patients endorsed fewer physical, practical, social/family, and spiritual concerns. Fourth, they reported being more satisfied with their overall health care team and medical care and reported being more likely to recommend their treating hospital. Fifth, the study identifies areas of

symptom management in ThyCa-P worthy of further inquiry and program development, notably preoperative and postoperative anxiety, fatigue, and depression, preoperative pain, and post-operative appetite and drowsiness.

Improvements following ITCA-ThyCa seem clinically meaningful and comparable to those found in other populations,<sup>30</sup> indicating that ThyCa-P at large may need further integrated care and support, rather than limiting this support to complex cases as suggested by ATA guidelines.<sup>1</sup> This study highlights that the needs of ThyCa-P may have been unintentionally minimized in light of an excellent medical prognosis. ThyCa-P' symptoms were comparable and even higher than previously reported in a cohort of 1274 oncology outpatients.<sup>31</sup>

<sup>&</sup>lt;sup>a</sup>Primary outcome.

<sup>&</sup>lt;sup>b</sup>Secondary outcomes.

<sup>&</sup>lt;sup>c</sup>P values based on ANOVA.

<sup>\*</sup>p <.05; \*\*p <.01; †trend.

**TABLE 3** Evolution of IG patients' clinical symptoms (ESAS ≥ 4&CPC) and difference with CG

		IG			CG	
Outcomes		Preop n(%)	Postop n(%)	P Value-PP		P Value-IG
ESAS	Well-being	20.0%	30.5%	.05*	59.0%	.001**
	Tired	41.7%	50.0%	.40	60.7%	.20
	Anxious	42.7%	28.7%	.003**	41.0%	.12
	Depressed	16.7%	17.2%	.66	21.3%	.53
	Pain	16.7%	11.5%	.51	25.0%	.03*
	Nausea	3.1%	8.0%	.13	9.8%	.71
	Drowsy	8.3%	21.4%	.005**	37.3%	.04*
	Appetite	8.2%	23.3%	.002**	45.9%	.004**
	Shortness of breath	7.3%	17.2%	.02*	31.7%	.04*
CPC	Fears/worries	29.9%	33.3%	.85	41.3%	.32
	Sleep	21.6%	34.8%	.58	39.7%	.54
	Sadness	19.6%	23.3%	.66	30.2%	.47
	Worry family/friends	18.6%	29.2%	.38	33.3%	.59
	Frustration/anger	18.6%	14.4%	.07	19.0%	.45
	Understanding illness/treatment	16.5%	19.1%	.60	23.8%	.48
	Work/school	15.5%	17.8%	.50	28.6%	.11
	Weight	15.5%	27.0%	.30	50.0%	.004**
	Talking with health care team	11.3%	18.0%	.41	17.5%	.93
	Treatment decision-making	10.3%	11.2%	.74	15.9%	.41
	Appearance changes	7.2%	10.0%	.48	20.6%	.07 <sup>†</sup>
	Concentration/memory	10.3%	16.9%	.41	38.1%	.003**
	Feeling burden to others	9.3%	10.1%	.74	15.9%	.29
	Finances	7.2%	17.8%	.01*	22.2%	.50
	Feeling alone	7.2%	10.1%	.71	22.2%	.04*
	Getting to/from appointments	6.2%	6.7%	1.00	14.3%	.12
	Meaning/life-purpose	5.2%	10.1%	.18	28.6%	.003**
	Accommodation	3.1%	2.2%	1.00	6.3%	.20
	Knowing resources	2.1%	6.7%	.57	14.3%	.12
	Intimacy/sexuality	1.0%	8.9%	.16	14.3%	.30
	Faith	1.0%	6.7%	.16	11.1%	.34
CPC domains	Emotional	43.3%	44.8%	.77	60.3%	.30
	Physical	30.9%	47.7%	.32	74.2%	.014*
	Social/family	24.7%	36.0%	.76	49.2%	.57
	Informational	23.7%	30.2%	.73	42.9%	0.68
	Practical	22.7%	30.2%	.28	49.2%	0.26
	Spiritual	5.2%	12.8%	.096 <sup>†</sup>	33.3%	0.29
	Total	80.1%	67.2%	.56	100%	.04*

Abbreviations: ESAS, Edmonton Symptom Assessment System; CPC, Canadian Problem Checklist; CSQ, Client Satisfaction Questionnaire; IG, intervention group; CG, comparison group; *P* Value-PP, *P* Value differences Pre-Post; *P* Value-IG, *P* Value Intergroup Differences.

\*p <.05; \*\*p <.01; †trend.

This minimization is further exemplified by the high levels of distress, eg, moderate-to-high anxiety in 43%. This high level of anxiety may be due to ThyCa-P' accumulation of known distress risk factors (eg, younger women with dependents at home and multiple life-roles; trajectory of care comprising a single medical visit presurgery; context of uncertainty and ambiguous decision-making in light of indeterminate biopsies; long treatment wait times compared to other cancer sites due to the cancer's slow-growing nature; and visible scar). The longer than usual surgical wait times, ie, more than 6 months from an identified thyroid abnormality, and render the stress response

chronic<sup>34</sup> and erode coping capabilities with additional challenges presurgery (eg, other life stressors) or postsurgery (eg, voice loss, fatigue, needing a second surgery, I-131-low-iodine diet, and isolation requirements). Notwithstanding the potentially damaging effects of long-term perseveration cognition (ie, worry, rumination, and anticipatory stress) and associated physiological impact on cardiovascular, immune, endocrine, and neurovisceral systems.<sup>35</sup> Within this context, it appears important in ThyCa to investigate how anxiety interfaces with and intensifies the experience of physical symptoms, as found in previous studies.<sup>36</sup> Also, warranted is investigating the impact of minimizing



TABLE 4 Interviewed patients' sociodemographic/medical characteristics and illustrative quotes

Sociodemographic / medical variables		n(%)/x(SD)
Gender	Female	11 (64.7%)
Age		45.2(16.5)
Marital status	Married/common-law	12 (70.6%)
Cancer	Papillary/follicular Medullary/anaplastic	16 (94.1%) 1 (5.9%)
Surgery	Total thyroidectomy Hemithyroidectomy	16 (94.1%) 1 (5.9%)
Neck dissection		1 (5.9%)
I-131		7 (41.2%)

#### Illustrative quotes:

- 1. "I didn't just call her once, I called her many times. She was always there, very supportive, and told me what to do. I felt secure, like I was being cared for."
- 2. "I said 'I'm tired' and she gave me resources to help manage my fatigue."
- 3. "It feels like very good quality of care, rather than just sporadic meetings with your doctor. Like taking an extra step towards the care of the patient."
- 4. "I had problems with my arm and the nurse immediately referred me to a physiotherapist, who gave me exercises."
- 5. "I would have panicked if she wasn't there!"
- 6. "You call the nurse and she's there for you, reassures you, she's on the spot."
- 7. "So she goes, 'try to walk as much as you can, don't over do it, carry-out your normal activity as much as possible.' If I didn't have that support, I would have been down, sitting down there and gaining weight like crazy."
- 8. "At first I became very emotional and cried because she was the first to name what I was feeling. Often people will say "yes but, you don't have breast cancer, you should feel lucky!" That's true, but I still have cancer. The nurse allowed me to feel anxious and afraid and I learned to become open to what I feel."

the ThyCa experience in light of excellent medical outcomes and how emphasizing medical facts reinforces vigilance-avoidance pathways shown to maintain the traumatic valence of life stressors<sup>37</sup> and its corollary poorer physical and psychological outcomes.<sup>38,39</sup>

# 4.1 | Limitations and clinical implications—IRB#13-063

While our study identifies for the first time, using a prospective longitudinal design, the potential need for further holistic integration of the care needs of ThyCa-P in oncology, several limitations are noteworthy. First, this study took place at a university-affiliated hospital in a Canadian urban city and thus may not reflect the care provided in other institutions or in rural settings. Second, it was not possible to randomize patients, neither to use a prospective design in both groups, which signals a barrier to randomize in this population and evidence of the distress level. However, analyses were adjusted for important confounders. Third, the nurse was bilingual and may have more readily facilitated access to care in French-speaking patients compared to usual. Lastly, this study focused on the early phases of diagnosis and treatment. Further research is needed to investigate longer-term adjustment into survivorship.

Data from our program challenge the idea that the care of ThyCa is "straightforward." While its medical course may well be, its experience is not, and medical care alone may not be sufficient. Further providing supportive resources to ThyCa-P seems warranted, including consideration of increased access to interdisciplinary care—clinicians can be an important source of social support, providing consistency in an unknown process with many transient people (ie, surgeons) and an expertise that most people do not receive from their traditional social support. At the very least, acknowledging the importance of a ThyCa diagnosis experience, even in the face of an excellent medical prognosis, seems necessary. This appreciation may not only lead to improved symptom recognition and management but also to better

integration of the experience in patients' lives. Considering further supporting data from future studies, the next could be to consider modifying treatment guidelines for this population accordingly.

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