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# Effectiveness of educational materials on levels of knowledge of thyroid associated orbitopathy in an endocrinology clinic

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### ABSTRACT

*Objective*: We aim to assess and quantify basic knowledge about TAO in patients presenting to an endocrinology clinic and the effect of different educational materials on patients' knowledge.

*Methods*: This study was conducted in a tertiary care center involving 255 patients presenting to an endocrinology clinic. The study was divided into three consecutive phases: 1. a control phase without any educational materials in the waiting room, 2. exposure to educational posters, and 3. exposure to educational pamphlets. *Results*: In the control population, only 16.5% of patients reported having knowledge of TAO, with a low average TAO-K score of 29.8 (out of 100). After the poster and pamphlet interventions, the percentage of patients having any knowledge of TAO increased across the control, poster and pamphlet phases: 16.5%, 25.9%, 63.5% respectively (p < 0.001). Similarly, the mean TAO-K score increased: 29.8, 45.8, 63.2 respectively (p < 0.001). *Conclusion*: This study confirms that patients with thyroid dysfunction have a low level of awareness and depth of knowledge of TAO.

*Innovation:* We suggest the dissemination of educational material to increase the knowledge of TAO in thyroid patients. This will help with early symptom detection and ensure proper management of this interdisciplinary condition.

## 1. Introduction

Thyroid-Associated Orbitopathy (TAO) is an autoimmune inflammation of orbital and periorbital tissue occurring in patients with thyroid disease. While it is most common in Graves' disease, patients with hypothyroidism and even those in a euthyroid state may suffer from it [1].

Patients with TAO often present for clinical evaluation many months after the onset of their ocular symptoms [2,3], thereby delaying the initiation of appropriate treatment measures. This could be due to insufficient awareness about the disease [2]. A recent paper by Edmunds & Boelaert found that patients with Graves' disease or TAO have significant misconceptions and only slightly better knowledge about the disease compared to healthy controls [4]. Since thyroid dysfunction and TAO occur within close temporal proximity in most patients [5], the endocrinology clinic seems then a valuable setting for raising patient awareness about the condition.

Educational materials in the clinic waiting room, such as posters and pamphlets, have been shown to have variable results with respect to

increasing patient knowledge about several diseases as well as prompting changes in patients' behavior [6-9]. In this study, we aim to assess the baseline level of knowledge of TAO in patients presenting to an endocrinology clinic, and the effectivity of different waiting room educational materials in improving awareness and depth of knowledge regarding TAO.

### 2. Methods

This is a single-center quasi-experimental study in the setting of a tertiary care center, involving 255 patients presenting to an endocrinology clinic. This study was approved by the Institutional Review Board of the American University of Beirut Medical Center and adheres to the tenets of the Declaration of Helsinki and Health Insurance Portability and Accountability Act Regulations. All participating subjects signed an informed consent form All primary endocrinologists of patients in the waiting area were informed about the study by email and approved recruitment of their patients. The study was conducted prior to the COVID-19 pandemic when no guidelines for social distancing were

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The study was divided into three consecutive phases of two weeks duration each. In the first phase, the control phase, there were no educational materials in the clinic waiting room. In the second phase, an A2-sized educational poster was hung on the waiting room wall in a central and easily visible location. In the third phase, educational pamphlets were distributed to all patients in the clinic waiting area. Both pamphlets and posters had exactly the same layout and provided identical information on TAO that include four risk factors, six symptoms and two alleviating factors. Only one risk factor (smoking), one symptom (red bulging eyes) and one alleviating factor (stopping smoking) were pictorially represented. Simple basic English and Arabic were used in all educational materials, as these are the two most spoken languages in the country with a literacy level of ~95% [10,11]. Simple basic English and Arabic were used in all educational materials written below 5th grade reading level. The literacy level of all individual participants was assessed to be above high school level, and illiteracy was an exclusion criterion.

A questionnaire to assess knowledge regarding TAO was devised. Prior to the clinical encounter with their endocrinologist, patients filled the questionnaire, answering questions about baseline demographics, smoking habits, presence of thyroid dysfunction and indicating whether they had any knowledge of TAO. Patients who noted having any knowledge of TAO answered questions assessing their level of knowledge on risk factors (11 questions), symptoms (9 questions) and alleviating factors (4 questions). Patients previously enrolled in any one phase were excluded from the next phases. Patients known to have active TAO were not included in the study. The questionnaire was developed using a focus group of two endocrinologists and two ophthalmologists, with the aim being to assess patient knowledge of TAO and to quantify the effect of different educational material using the TAO-K score. The knowledgebased questions included were derived from two previously validated questionnaires used to explore patient knowledge and facilitate early diagnosis of thyroid-associated orbitopathy [4,12]. The administered questionnaire was not piloted prior to the commencement of the study.

Patients were classified into 2 groups within each phase: those at risk of developing TAO, including patients with hyperthyroidism or hypothyroidism, and those from the remaining patient population who are at low risk of developing the disease. Two main outcomes were compared among the three phases. The first is the proportion of patients reporting having any knowledge of TAO which reflects general awareness. The second is a customized TAO knowledge (TAO—K) score assessing the level of knowledge in patients who answered to having any knowledge of the disease. The TAO-K score was calculated from the multiple-choice questionnaire by summing up the number of correct answers, then subtracting the number of incorrect answers, and dividing it by the total number of possible correct answers. Patients that answered as having no knowledge of TAO did not complete the rest of the questionnaire and were excluded from the score computation.

Statistical analysis was done using IBM SPSS v23. Categorical outcomes were compared using the Chi-square test, and continuous outcomes by one-way Analysis of Variance (ANOVA) or the Kruskal-Wallis test when normality could not be assumed. Post-hoc pairwise comparisons were done using the z-test to compare column proportions for categorical variables and one-way ANOVA for continuous variables (or the Dunn test when normality was not assumed), applying the Bonferroni correction to adjust for multiple testing. Cramer's V test was used to measure the strength of the associations in chi-square tests and Eta squared was used to measure of effect size for one-way analysis of variance (ANOVA) models. Logistic regression analysis was used to evaluate the relationship between various predictor variables (either categorical or continuous) and on a single dichotomous outcome. An alpha level of 0.05 was used for all statistical tests.

### 3. Results

### 3.1. Demographics

A total of 255 patients participated in the study, with 85 patients completing the survey in every phase. There was no statistical difference in baseline characteristics among the three phases of the study including age, gender distribution, smoking status and prevalence of thyroid disease (Table 1). A total of 108 patients (42.5%) had some form of thyroid disease. Among them, 52.8% had hypothyroidism, 21.3% had hyperthyroidism, 19.4% had a thyroid nodule, 2.8% had thyroid cancer. Each of these diagnoses was similarly prevalent in all 3 phases of the study except for thyroid cancer that were only present in phase 2 (Table 1).

### 3.2. Control group

In the first phase of the study where the control population was not exposed to any educational materials, only 16.5% reported having any knowledge of TAO. This percentage was higher in patients with hyperthyroidism or hypothyroidism (30.8%) who are at a higher risk than the general population to develop TAO, compared to percentage of the rest of the control group that are at low risk of developing the disease (10.2%) (p=0.027). (Fig 1) On the other hand, the objective TAO-K mean score that reflects patient's depth of knowledge was relatively low and did not statistically differ in between patients with hyper-or hypo-thyroidism who are at risk for TAO (34.4  $\pm$  15.1) and patients at low risk of developing the disease (23.6,  $\pm$ 18.6) (p=0.27). (Fig 2).

### 3.3. Poster and pamphlet intervention

The percentage of patients having any knowledge of TAO increased across the three study phases: 16.5%, 25.9%, 63.5% respectively in the control, poster and pamphlet groups ( $\chi^2 = 46.16, p < 0.001, V = 0.425$ ). Similarly, the mean TAO-K score increased across the three study phases: 29.8, 45.8, 63.2 in the control, poster and pamphlet groups respectively ( $F(2, 87) = 20.2, \eta^2 = 0.317, p < 0.001$ ). Logistic regression analysis showed no statistically significant effect of age or gender on patient knowledge (p = 0.092), or the mean TAO-K score (p = 0.08).

In both the poster and pamphlet study phases, and in contrast to the control phase, there was no significant difference in the percentage of

**Table 1**Baseline patient characteristics of the control, poster and pamphlet groups.

	Total Sample	Control	Poster	Pamphlet	<i>p</i> -value
Patients (n)	255	85	85	85	
Mean Age (years, SD, range)	49.6 ( $\pm 16.1$ ) [18–90]	50.4 (±17)	49.7 (±16)	48.8 (±16)	0.81
Female Gender (n, %)	162 (63.5%)	51 (60.0%)	55 (64.7%)	56 (65.9%)	0.7
Smoking (n, %)					
Never	135	46	41	48	
	(52.9%)	(54.1%)	(48.2%)	(56.5%)	
Previous smokers	26 (10.2%)	8 (9.4%)	13 (15.3%)	5 (5.9%)	0.52
Current Smokers	94 (36.9%)	31 (36.5%)	31 (36.5%)	32 (37.6%)	
Thyroid Disease		, ,	, ,	, ,	
(n, %)					
Total *	108	33	36	39	0.65
	(42.5%)	(38.8%)	(42.4%)	(45.9%)	0.03
Hypothyroidism ^	57 (52.8%)	18	19	20	
Hyperthyroidism ^	23 (21.3%)	8	6	9	
Thyroid nodule ^	21 (19.4%)	7	8	6	0.08
Thyroid Cancer ^	3 (2.8%)	0	3	0	
Unspecified ^	4 (3.7%)	0	0	4	

<sup>\*</sup> Percentage of total sample population.

Percentage of patients with thyroid dysfunction.

W.J. Kheir et al. PEC Innovation 3 (2023) 100225

## TAO-KNOWLEDGE (Figure 1)

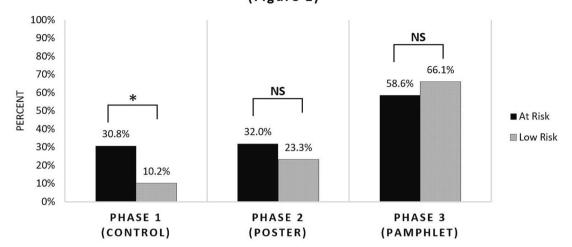


Fig. 1. Percentage of patients with knowledge of TAO in the control, poster and pamphlet study phases, stratified into high risk and low risk patients. \* p < 0.05; NS: Not Significant.

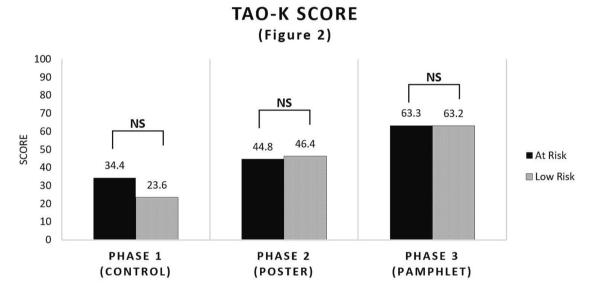


Fig. 2. Mean TAO-K score (out of 100) in control, poster and pamphlet phases, stratified into high risk and low risk patients. \*p < 0.05; NS: Not Significant.

patients having knowledge (or in the mean TAO-K score) in between the two subgroups of patients with higher risk (hyper- and hypo- thyroid) or low risk of developing thyroid eye disease. (Figs  $1\ \&\ 2$ ).

## 3.4. TAO knowledge

In the multiple-choice patient questionnaire, 'Smoking' and 'Thyroid Dysfunction' were the most correctly identified risk factors by 84% and 78% of patients, respectively. Similarly, 'Smoking Cessation' was the most identified prevention strategy by 81% of patients. As for disease symptoms, 'Bulgy red eyes' and 'Pain' were correctly identified by 92% and 80% of patients respectively. The most significant misconception was 'Eye infection' that was incorrectly identified as a presenting symptom by 34% of patients. Nearly half of the patients (46%) were unaware of the therapeutic benefit of selenium in TAO. (Fig 3)

### 4. Discussion and conclusion

### 4.1. Discussion

Thyroid associated orbitopathy is diagnosed around 7–16 months after the onset of ocular symptoms [2,3]. Treatment interventions for TAO are mostly beneficial during the active phase of the disease [13,14], and effective treatment can decrease morbidity when initiated early [15]. Thus, an early diagnosis appears to be beneficial in reducing some of the disfiguring disease manifestations such as proptosis, diplopia and optic nerve compression. This is in addition to improving quality of life, psychosocial and indirect public health costs of more advanced treatments and loss of work productivity [16,17].

Since thyroid dysfunction usually precedes TAO and occurs within 18 months of each other in around 60–85% of patients [5], then an endocrinology clinic is the ideal set up to increase awareness about this disease. Awareness can involve either patients and/or physicians. In fact, the PREGO study compared the EUGOGO surveys 12 years apart

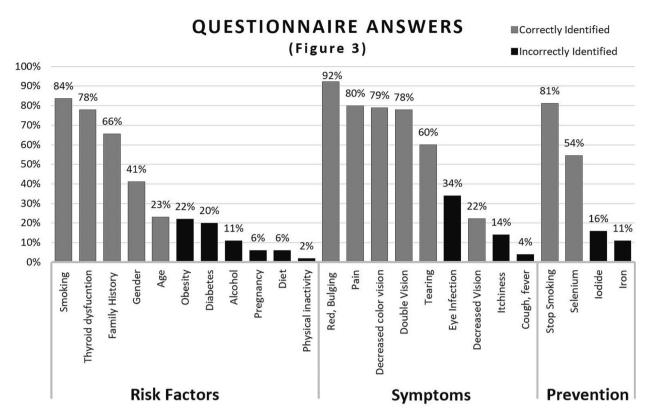


Fig. 3. Percentage of correctly and incorrectly answered questions on the patient questionnaire, stratified into risk factors, symptoms and prevention strategies for TAO.

found a reduction in the 'time from first symptoms to diagnosis' over the years. They attributed this reduction to an increase in physician awareness and fund of knowledge about TAO because of an increased scientific discussion on the topic [2]. Primary care health education of disease is another critical approach for increasing patient awareness [18].

As for patient awareness, only few studies have been published regarding this particular disease. Edmunds and Boelaert were recently the first to publish on TAO knowledge in Graves' disease patients. Although Graves' disease patients constitute about 90% of patients with TAO, they were found to score slightly higher than healthy controls on a TAO knowledge questionnaire, with the small difference believed to be practically insignificant [4]. Furthermore, these patients at high risk were also found to have several misconceptions about TAO [4]. In our study, we similarly only found 30.8% of patients with risk for thyroid eye disease to have any knowledge of TAO. And looking into the depth of knowledge, we also found their level of knowledge to be superficial, as the objective TAO-K score was relatively low (34.4/100) and not significantly different from their counterparts with low risk of developing thyroid eye disease (23.6/100). This shallow understanding of basic concepts raises the necessity to increase TAO awareness to help patients at risk in recognizing early symptoms and achieving an early diagnosis.

## 4.2. Innovation

A few educational modalities have been suggested to increase patient awareness and knowledge. Online resources about TAO have been found to have a low readability [19]. Warning cards on early signs and symptoms distributed to Graves' disease patients have shown some benefit [20], as well as a symptom-based patient questionnaire to help identify TAO patients for an early referral [12]. Waiting room posters and pamphlets have not been studied in TAO. They have shown variable results with respect to increasing disease awareness, fund of knowledge

and prompting further conversation in many other disease conditions. Multiple factors affect the expected outcome including the educational material design attractiveness, and time spent in waiting room as well as patient demographics including age, gender and educational level [7,21]. Furthermore, many papers on the subject have studied the effect of posters and pamphlets grouped together; and failed to objectively check whether any patient-reported increase in awareness is actually reflected in an increase in depth of knowledge [7,8,21]. This is why we opted to assess the effect of posters and pamphlets in two consecutive phases to showcase their effectiveness separately.

In our study, we found pamphlets to be more effective than posters in increasing patient awareness on TAO compared to a control population, as well as the depth of knowledge on TAO that was reflected by a significant increase in the custom TAO-K score. We postulate that the active distribution of pamphlets commands immediate patient attention, compared to the passive exposure of posters on walls, to be the reason for the increased effectiveness of pamphlets. Pamphlets also have the advantage of continued availability of educational materials as patients can take them home for further reading. These results are also reflected in the literature, where multiple papers on pamphlets or leaflets showed more robust positive results in increasing knowledge and stirring conversation with their physician on different target diseases [9,22,23], compared to posters that had varied results [21,24,25].

The differential health literacy between patients is a possible confounding factor in the assessment of patient knowledge. This is why both posters and pamphlets in this study had exactly the same design, font, color and images to preclude any pictorial bias. Interestingly, the most correctly answered questions were 'smoking' and 'red bulgy eyes' that were both pictorially illustrated in the educational materials. This exemplifies the augmented effect of graphics over text in patient education, as the association of smoking with TAO was mostly unknown by patients in previous studies [4].

#### 4.3. Conclusion

This study has a few limitations. It examines the general ability of posters and pamphlets to increase knowledge about TAO -in a population at higher risk- but is not powered enough to detect their effects specifically on patients with Graves' disease. It also does not assess for retention of information over longer time periods, when patients are still at risk of developing TAO. We also acknowledge that it is not possible for us to guarantee the wider applicability of the results of this study. However, the study was conducted at a primary tertiary hospital using a large sample of patients and represents an unbiased cross-section. Future studies are needed to gauge patient knowledge and develop educational materials that address existing gaps in knowledge more accurately.

This study confirms the need for increasing patient education about TAO, as patients in an endocrinology clinic waiting room were found to have a low level of awareness and depth of knowledge. It is the first study to quantify the effect of different educational material on TAO. It shows pamphlets to have better results than posters in increasing awareness and knowledge of the condition. Larger studies are needed in the future to focus on patients with thyroid dysfunction only, as well as on higher levels of knowledge including long term retention and behavioral modification, mainly in presentation to ophthalmology clinics for examination.

### Author contribution

RA designed and directed the project. RA, WJK, AAK, JT, RI were involved in data collection. RA, WJK, AAK, JT, RI were involved in the statistical analysis and interpretation of results. RA, WJK, AAK, JT, RI drafted the manuscript and designed the figures. All co-authors contributed to critically revising the manuscript and read and approved the final version.

### **Declaration of Competing Interest**

The authors have no financial disclosures or conflicts of interest to declare. This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

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