Original Article

Patient's knowledge and perception about hypothyroidism : Indian perspective

Deepak Khandelwal[1], Deep Dutta[2], Sachin Chittawar[3]

Primary hypothyroidism is one of the commonest endocrine disorders in clinical practice. Patient's knowledge and perception towards disease is very important for long term outcome in any chronic disease. Available literature suggests that large number of patients with primary hypothyroidism lack basic knowledge about the disease and its treatment in India even among well educated class. Dietary as well as treatment related false believes, faulty practices related to treatment as well as issues with compliance are also very common. Public health measures are required to improve knowledge and awareness regarding the disease in patients with primary hypothyroidism for better long term outcome in India.

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Key words **: Hypothyroidism, India, KAP, knowledge, awareness, practices, patient education, compliance.**

Primary hypothyroidism is a common endocrine disorder in clinical practice. Patient's knowledge, perception and awareness about the disease and its treatment are very important for good long term outcome and compliance in any chronic disease. Aim of this review is to explore data regarding KAP (knowledge, awareness and practices) among Indian hypothyroid subjects, its public health implications and possible solutions to improve it in clinical practice.

Epidemiology of Hypothyroidism in India :

Hypothyroidism denotes deficient production of thyroid hormone by the thyroid gland and can be primary (abnormality in thyroid gland itself) or secondary/central (as a result of hypothalamic or pituitary disease). Subclinical hypothyroidism is that grade of primary hypothyroidism in which there is an increased TSH concentration in the presence of normal serum thyroxine (T4) and triiodothyronine (T3) concentrations[1].

Primary hypothyroidism is the cause of hypothyroidism in more than 99% of cases. Primary hypothyroidism is a very common disorder. It is more common in women and increases in incidence with age. The worldwide prevalence of overt hypothyroidism is between 1% and 2%, while approximately 8% of women and 3% men have subclinical hypothyroidism[2]. The disease is rather more common in the Indian scenario and overt hypothyroidism has been reported between 3.5% and 4.2% while subclinical hypothyroidism has been reported in 8.02%–19.3% of population in various studies across India[3,4].

Society for Promotion of Education in Endocrinology and Diabetes (SPEED) Group, India

[1]Department of Endocrinology, Maharaja Agrasen Hospital, Punjabi Bagh, New Delhi 110 026 and Corresponding author

[2]Department of Endocrinology, Diabetology & Metabolic Disorders, Venkateshwar Hospitals, New Delhi 110075

[3]Division of Endocrinology, Department of Medicine, Gandhi Medical College (GMC) and Hamidia Hospital, Bhopal 462001

- **Primary hypothyroidism is the cause of hypothyroidism in > 99 % of cases.**
- **KAP (knowledge, awareness and practices) are lower among Indian patients.**
- **KAP helps earlier diagnosis with long term treatment compliance and outcome.**
- **Doctors in India should be more sensitive about their clinical practice.**

Importance of Disease Awareness and Perception among Patients in Chronic Diseases :

Studies have clearly shown the importance of improving patient's knowledge through education and associated benefits of improving compliance for patients with chronic diseases like hypertension and diabetes[5,6], although such data is scarce in context of hypothyroidism[7]. Hypothyroidism has profound impact on general health and well-being. Globally, thyroid disorders continue to be common yet one of the most under- diagnosed and neglected chronic health conditions[8,9]. Better knowledge and understanding of their disease will encourage patients to be more complaint with T4, follow up regularly and spread correct facts to their relative and friends.

Thyroid KAP : Indian Data :

We recently published a cross-sectional observational KAP study involving 250 subjects of primary hypothyroidism who had been diagnosed and receiving treatment for at least 3 months and came to our centre for the first

time[10]. The mean age of the participants was 43.24 ± 10.80 years; with 85.6% of subjects being females. The median duration of hypothyroidism was 8 years and most subjects were well educated, with 53.6% being graduates/post-graduates. However, in spite of long standing disease and well educated subjects, knowledge and awareness related to hypothyroidism was poor in majority of participants. Only 35.2% and 51.2% knew correct meaning of the terms "thyroid" and "hypothyroidism" respectively. Three forth of subjects did not knew that T4 is used to replace and normalize blood levels of thyroid hormone. Forty percent subjects had false dietary beliefs in the context of hypothyroidism. Ten percent participants felt T4 can be stopped once laboratory reports return to normal. Only 36.4% participants knew correctly that T4 need to be continued during pregnancy. A significant number (7.2%) of participants were nonadherent to T4. Other studies across India have also shown that large number of patients with primary hypothyroidism, their family members as well as general population lack basic knowledge about the disease; have lot of misconceptions related to nature of disease, dietary precautions and treatment of hypothyroidism[11-14]. Also, across studies, there is a significant deficit regarding adherence to treatment[15].

Thyroid KAP: India versus Rest of the World :

An interesting study from USA showed that increased KAP regarding hypothyroidism in the general population was associated with earlier diagnosis and treatment of hypothyroidism[16]. Patients without awareness of hypothyroidism were more likely to remain undiagnosed and untreated adding to increased morbidity. Another study from Brazil also showed that public disclosure of possible risk factors of hypothyroidism creates more awareness in the general population and possibility of early diagnosis[17].

Public Health Implications & Possible Solutions :

Causes of poor KAP among patients can be multiple. One of the important factor contributing to this gap observed is the limited number of thyroid specialists in the country and lack of awareness among primary healthcare physicians[18,19]. Inadequate time spent by doctors for patient education because of their heavy patient load is another important factor. Patient related factors include inadequate education, social beliefs and not using or incorrect information acquired from the social media and internet[20].

It is well known that thyroid disease is not a major cause of mortality but it can be cause of multiple comorbidities like osteoporosis, dyslipidemia, cardiovascular and neuropsychiatry diseases[1]. Inappropriate knowledge regarding disease and its treatment leads to poor outcome of disease. Patients tend to discontinue treatment in hypothyroidism once their laboratory reports become normal. Also they tend to spread wrong knowledge to their relatives and friends as well.

There is a need for structured educational programmes to improve the understanding and awareness of hypothyroidism among doctors, patients as well as general population. While there are various media programmes for other chronic diseases like diabetes and hypertension, there are not enough educational activities for thyroid disorders. Healthcare physicians should spend adequate time for comprehensive education of the patients in order to improve patient care[21]. Patients should be empowered adequately for long term better outcomes[22,23].

Patient education needs to be modified depending on education level, socioeconomic status and social culture and believes of subjects. In educated patients, information sheets explaining about the disease or to have a few pictorial/pamphlets about the disease, will likely work. However, quality and appropriateness of printed materials need to be ensured. Oral presentations and visual presentations to convey necessary medical information through one-on-one teaching, audiotapes, and videotapes, will work better for persons who have inadequate or marginal literacy.

Conclusion :

KAP regarding hypothyroidism seems lower in India among patients with hypothyroidism as compared to rest of the globe, although studies are limited. Doctors in India should be more sensitive about the specific queries and complaints of patients with hypothyroidism in their clinical practice to improve long term treatment compliance and outcomes.

References

1 Khandelwal D, Tandon N — Overt and subclinical hypothyroidism: Who to treat and how. *Drugs* 2012; **72:** 17-33.

2 Vanderpump MP, Tunbridge WM, French JM, Appleton D, Bates D, Clark F, *et al* — The incidence of thyroid disorders in the community: A twenty-year follow-up of the Whickham Survey. *Clin Endocrinol (Oxf)* 1995; **43:** 55-68.

3 Marwaha RK, Tandon N, Ganie MA, Kanwar R, Sastry A, Garg MK, *et al* — Status of thyroid function in Indian adults: Two decades after universal salt iodization. *J Assoc Physicians India* 2012; **60:** 32-6.

4 Kalra S, Kumar A, Jarhyan P, Unnikrishnan AG — Indices of thyroid epidemiology. *Indian J Endocrinol Metabol* 2015; **19:** 844-7.

5 Heisler M, Pietee JD, Spencer M, Kieffer E, Vijan S — The relationship between knowledge of recent HbA1c values and diabetes care understanding and self management. *Diabetes Care* 2005; **28:** 816-22.

6 Williams MV, Baker DW, Parker RM, Nurss JR — Relationship of functional health literacy to patients' knowledge of their chronic disease. A study of patients with hypertension and diabetes. *Arch Intern Med* 1998; **158:** 166-72.

7 Crilly M, Esmail A. Randomized controlled trial of a hypothyroid educational booklet to improve thyroxine adherence. *Br J*

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Gen Pract 2005; **55:** 362-68.
8 Kalra S, Unnikrishnan AG, Sahay R — The global burden of thyroid disease. *Thyroid Res Pract* 2013; **10:** 89-90.
9 Kalra S, Unnikrishnan AG, Baruah MP — Thyroid: Disorders of a lesser gland. *Thyroid Res Pract* 2013; **10:** 45-6.
10 Kumar P, Khandelwal D, Mittal S, Dutta D, Kalra S, Katiyar P, *et al* — Knowledge, Awareness, Practices and Adherence to Treatment of Patients with Primary Hypothyroidism in Delhi. *Indian J Endocrinol Metab* 2017; **21:** 429-33.
11 Goel A, Shivaprasad C, Kolly A, Pulikkal AA, Boppana R, Dwarakanath CS — Frequent Occurrence of Faulty Practices, Misconceptions and Lack of Knowledge among Hypothyroid Patients. *J Clin Diagn Res* 2017; **11:** OC15-OC20.
12 Kannan S, Mukundan L, Mahadevan S, Sathya A, Kumaravel V, Bhat RV, *et al* — Knowledge, awareness and practices (KAP) among patients with hypothyroidism attending endocrine clinics of community hospitals in Chennai. *Thyroid Res Pract* 2010; **7:** 11-5.
13 Singh A, Sachan B, Malik NP, Sharma VK, Verma N, Singh CP — Knowledge, awareness and practices (KAP) among patients with thyroid swelling attending Cytology Clinic in a Medical College, Meerut. *Sch J Appl Med Sci* 2013; **1:** 793-5.
14 Rai S, Sirohi S, Khatri AK, Dixit S, Saroshe S — Assessment of knowledge and awareness regarding thyroid disorders among women of a cosmopolitan city of central India. *Natl J Community Med* 2016; **7:** 219-22.
15 Mithal A, Dharmalingam M, Tewari N— Are patients with primary hypothyroidism in India receiving appropriate thyroxine replacement? An observational study. *Indian J Endocrinol Metab* 2014; **18:** 83-8.
16 Canaris GJ, Tape TG, Wigton RS — Thyroid disease awareness is associated with high rates of identifying subjects with previously undiagnosed thyroid dysfunction. *BMC Public Health* 2013; **13:** 351.
17 Zaccarelli-Marino MA, Saldiva André CD, Singer JM — Overt Primary Hypothyroidism in an Industrial Area in São Paulo, Brazil: The Impact of Public Disclosure. *Int J Environ Res Public Health* 2016; 13(11).
18 Surana V, Aggarwal S, Khandelwal D, Singla R, Bhattacharya S, Chittawar S, *et al* — A 2016 clinical practice pattern in the management of primary hypothyroidism among doctors from different clinical specialties in New Delhi. *Indian J Endocrinol Metab* 2017; **21:** 165-77.
19 Kalra S, Khandelwal D, Aggarwal S — Thyroid Vigilance. *Indian J Endocrinol Metab* 2017; **21:** 492-4.
20 Perumal SS, Prasad S, Surapaneni KM, Joshi A — Health information-seeking behavior among hypothyroid patients at Saveetha Medical College and Hospital. *Ethiop J Health Sci* 2015; **25:** 147-54.
21 Kalra S, Unnikrishnan AG, Tiwaskar M, Sahay R, Saboo B, Negalur V, *et al* — Medication Counseling for Thyroxine. Indian J Endocrinol Metab 2017; **21:** 630-1.
22 Kalra S, Unnikrishnan AG, Skovlund SE — Patient empowerment in endocrinology. *Indian J Endocrinol Metab* 2012; **16:** 1-3.
23 Rehman H, Rehan SJ, Ishaq H, Shakeel S, Hashmi F, Naveed S — Hypothyroidism—a question towards quality and patient centricity. *Open J Endocr Metab Dis* 2015; **5:** 19-27.