“Being well-informed is a prerequisite for the involvement of patients in clinical decision-making in Thyroid cancer care. A UK-based longitudinal, qualitative study”

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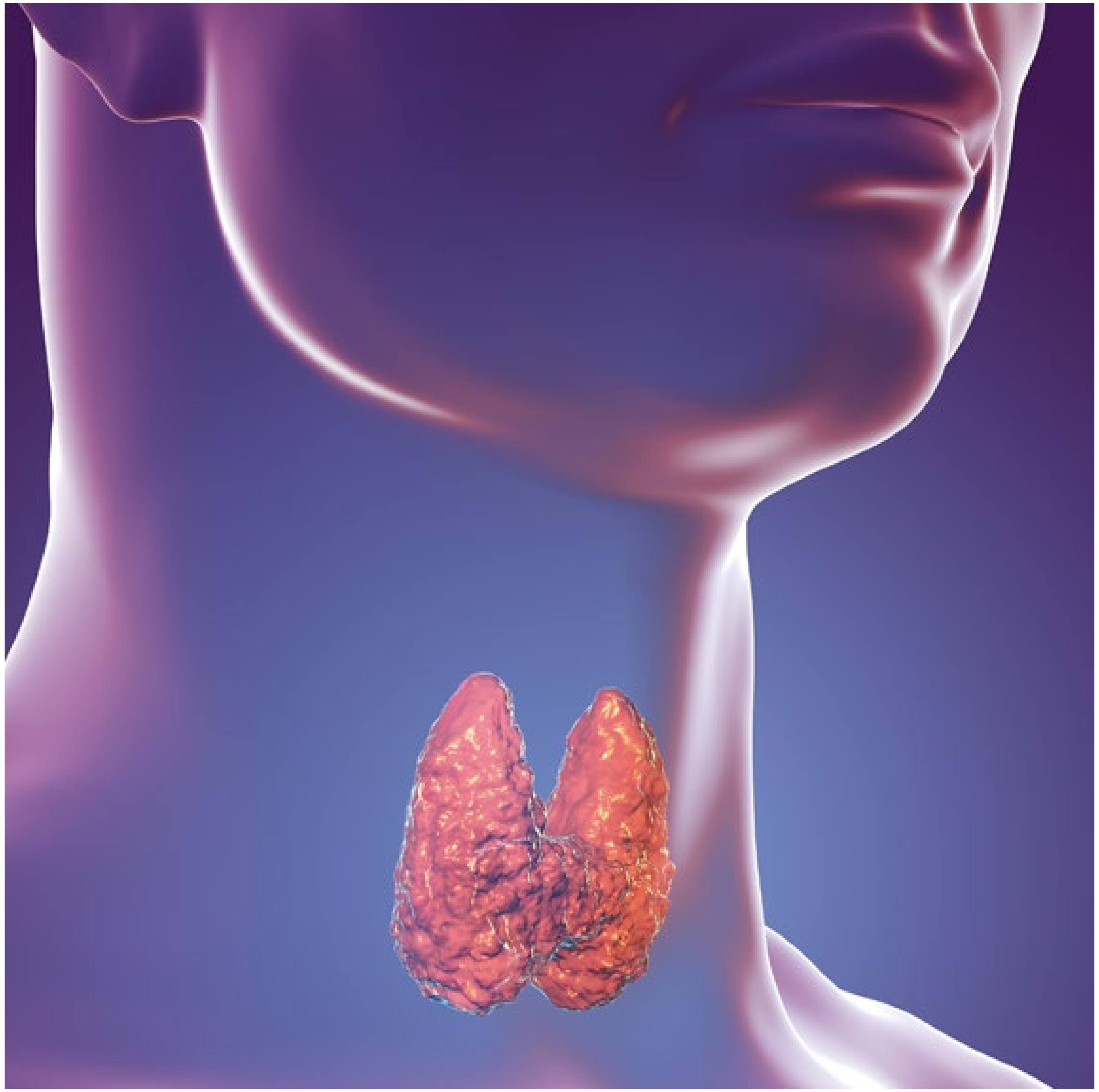
Introduction:
What is thyroid?



Introduction- Thyroid Cancer

- Thyroid cancer is relatively rare. Globally there were approximately 255,490 new cases in 2017 (Deng *et al.,* 2020). In the UK, the current annual incidence rate stands at 3,865 new cases between 2016 and 2018 (Cancer Research UK, 2024).
- It is the 20th most common cancer type in men and the 17th in women. It's 10-year survival rate is 85% (Cancer Research UK, 2024),
- Prevalence has more than doubled since the 1990s and it is predicted that it will rise by three-quarters by 2035 (Cancer Research UK, 2024). Thyroid cancer is more commonly diagnosed in women. A recent meta-analysis conducted by Mannathazhathu *et al*. (2019) suggests that this gender disparity may be linked to hormonal fluctuations during the menstrual cycle and pregnancy.
- NUTH has about 100 patients a year

Most common thyroid cancers

- Papillary (90%)
- Follicular (4%)

(Cancer Research UK, 2021)

Treatment for thyroid cancer

- Investigations (ultrasound, Fine needle aspiration- biopsy, diagnostic hemithyroidectomy)
- Total Thyroidectomy
- Hemithyroidectomy (lobectomy)
- Radioactive Iodine therapy (RAI) is a treatment in which radioactive iodine is used following total thyroidectomy to remove any remaining thyroid tissue cells. It decreases the risk of the recurrence of local and distant thyroid cancers
- Lifelong follow-up with Levothyroxine supplementations
- Active surveillance is an option that is more and more popular (Mallick *et al.,* 2018).

Introduction: What do we know so far?

Studies have shown that patient participation in decision-making does not always occur (Herrmann *et al*., 2019), and physicians may overestimate their information provision (James *et al*.,2018).

Specific areas where information provision is deemed inadequate include emotional and psychological support, dealing with side effects and emotions, and accessing up-to-date information about thyroid cancer as well as long-term effects (Morley and Goldfarb 2015; Sawka *et al*. 2016; Hyun *et al*., 2016).

Thyroid cancer survivors may experience long-term side effects and complications such as memory problems, headaches, psychological issues, and symptoms related to thyroid hormone suppressive therapy (Easley, Miedema and Robinson, 2013). There are also many side effects of different treatments (Buchmann *et al.*, 2015; Hedman *et al.*, 2017) and a big impact on quality of life (Singer *et al.,* 2016; McIntyre *et al.,* 2018a). Hence, it is pivotal for patients to be well informed in making decisions.

There is an increasing number of cases of overdiagnosis, especially in low-risk, well-differentiated thyroid cancer (Li *et al*., 2020). Highlighting the fact that well-informed decision-making is crucial, especially concerning pre-operative individual (Pitt *et al*., 2019).

Recent advancements in medical treatment for thyroid cancer have introduced a patient-centric approach, emphasising individualised, multidisciplinary clinical decision-making that closely involves patients (Mallick *et al.,* 2018).

- The study's primary objective was to qualitatively explore the lived experience of patients with TC and the factors that affect it. The secondary objective was to focus specifically on hospital care and treatment experiences, including the adequacy of the information provided to patients and their involvement in decision making.

Methodology: Sampling and Recruitment

Sampling method: Purposive sampling

Target- 25

Recruitment

1. Through CNS –Clinical Nurse Specialist – Local Collaborator

- potential participant identification
- giving patients PIS and consent for contact
- A local PI from the Trust was appointed

2. Advert placed by BTCT

Ethics Approval and Governance

- ☐ Northumbria University Ethics Approval
- ☐ Northumbria University NHS Ethics team Approval
- ☐ HRA (Health Research Authority) approval using IRAS application
- ☐ NHS Research Ethics Committee meeting 11th June 2019
- ☐ R & D approval from NUTH
- ☐ Caldicott Approval

Methodology: Inclusion Exclusion for Interviews

Inclusion Criteria:

1. Adult (over 18)

2. Within 8 weeks of the Diagnosis of Papillary, Follicular or Medullary Thyroid Cancer.

(or last 5years for Retrospective longitudinal participants)

3. Able to give informed consent.

Exclusion Criteria:

- 1. Diagnosis of Anaplastic Thyroid Cancer
- 2. Diagnosis of Terminal Thyroid Cancer
- 3. Co-diagnosis of different than thyroid terminal cancer

Methods of data collection

Interviews:

In depth semi-structured interviews with cancer patients.

Diaries:

For prospective longitudinal participants

Methodology: Time scale for data collection

1st Initial interview + handing out diaries

1-6 month

2nd interview - depends on the treatment pathway.

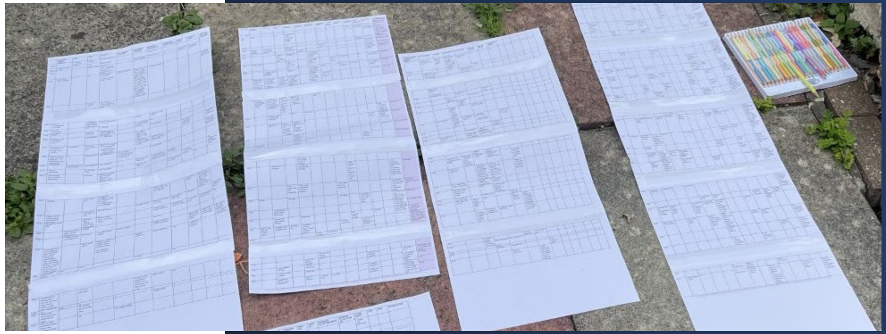
6-12m month

3rd interview. 6m-12m after 1st interview.

Data Analysis.

Giorgi’s descriptive phenomenology method of data analysis (Giorgi, 2009) using Nvivo.

Content analysis



Results: The key themes from the text include:

- **Theme 1. Lack of previous knowledge regarding thyroid cancer:** Many participants lacked awareness about thyroid cancer, which increased shock and confusion following their diagnosis.
- **Theme 2. Involvement in decision-making**: Some participants felt they were not sufficiently involved in decision-making regarding their treatment and, in some cases, regretted not being given more options.
- **Theme 3. Information provision at diagnosis:** While most participants felt they received adequate information, some reported feeling inadequately informed and needing more support to retain the information provided.
- **Theme 4. Gaps in the information provided**: Participants identified specific areas where they felt the information provided was lacking, including details about treatment side effects, post-surgery challenges, long-term symptoms, and information about taking levothyroxine.
- **Theme 5. Sources of information:** Patients received initial information from various sources, including consultants, specialist nurses, information packs, and online communities. Some participants sought information from the internet and social media, while others had questions about whom to contact for further clarification.
- **Theme 6**. **Regret.:** Some participants had regrets regarding the treatment that they underwent. Their decision has an impact on their life and future both in physical and psychological aspects.

Theme 1 .	**Lack of previous knowledge regarding thyroid cancer**	***'No, I've never, I've never heard about thyroid cancer (…). And quite few of my friends have said the same, they didn't even know that such a thing exists …'TC01***
Theme 2.	**Information provided at diagnosis**	*'I don't feel like I received much information at all, I would rather know everything and decide which one I would choose, rather than just some information here and there, I would rather have the full picture.'TC03*
Theme 3.	**Involvement in treatment decision-making**	***'(…)I think further down the line when I've seen the oncologist after my surgery she gave me a video from BTCT, which was very informative, but before my surgery I don't think I was as well informed as I could have been, definitely there was lack of information. I didn't realise what impact it can have, it has been a steep learning curve'.TC18*** ***So basically, the recommendation from the doctors' multidisciplinary meeting was that I should have therapeutic RAI at a 3.7 dose. However, I felt that there was insufficient evidence to suggest the need to have the RAI - there is no proof that there are any remaining cancer cells. NHS02***
Theme 4.	**Gaps in the information provision**	*I know levothyroxine you are not supposed to take with calcium, I was never told that by the nurses, I was taking them all together, I read it in the leaflet, that they are not meant to be taken together. TC01int2*
Theme 5.	**Sources of information**	*My consultant gave me a piece of paper, really useful really, it was how they grade the cancers according to look and age. And information about the procedure and follow up. She told me from the start not to look at American websites as they grade differently, so I only looked at British. I used BTF and BTCT for sources of information. TC02*
Theme 6.	**Regret**	*(…) Not having my right part of my thyroid removed as well where there was no cancer whatsoever, would save me from taking a life of medication and this palpitation. NHS02int3*

DISCUSSION

- It seems that having thyroid-specific information is very important. (Husson *et al.*, 2013) and (Wiener *et al.,* 2019) agreed that a good level of disease-specific information improves disease perception and coping.
- The study confirms that regretting RAI was low among their study participants (Sawka *et al.*, 2012). However, the author argues that many participants were still not adequately informed.
- The study agrees that information provision is one of the significant factors impacting the experience of people with thyroid cancer (Wiener *et al.*, 2019)
- The present study's participants reported some important gaps in information provision. Three significant gaps in information provision reported by participants in this study were physical aspects following surgery, including long-term physical symptoms, the psychological aspects of the cancer journey and psychological support, and practical levothyroxine information. It is supported by literature (Morley and Goldfarb, 2015; James *et al.*, 2018).

The study suggests that there are gaps in information provision regarding the timing of information provision and certain areas. This study argues that without adequate information, patients cannot be expected to make valuable contributions to decisions about their care, especially now, with more evidence of overdiagnosis and significant long-term implications of treatment and follow-up.

Potential Bias:

Self-selection bias (self-referral sampling)

Recall bias

Recommendations

Patients with Thyroid cancer should receive comprehensive thyroid-cancer-specific information

The information packs should contain more information about the areas identified as gaps in information provision

Patients should be counselled about the risks of complications and information about overdiagnosis.

As many patients are not aware that they can make decisions, they need to be aware that they can make “executive decisions” in their care.

Conclusions

The study emphasises the importance of **patient information** in thyroid cancer care. While some participants were satisfied with the information provided, others felt it was not timely or specific enough, expressing a desire for more detailed information on the impact of thyroidectomy and the long-term physical and psychological effects of treatments.

The findings underscore the urgent need for improved information provision to empower patients in their treatment **decision-making**.

Key message: Modern medicine involves patients in treatment decision-making. However, without timely, TC-specific information, patients cannot be expected to participate in "executive decision-making" or "authentic decision-making." Hence, being well informed is a pre-requisite for treatment decision making by patients.

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QUESTIONS?

Thank you ☺