



Unmet needs of people with thyroid cancer during and following treatment for well-differentiated thyroid carcinoma in the UK.

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INTRODUCTION

Thyroid cancer is the most common thyroid neoplasia. It is a comparatively uncommon and low-mortality cancer. According to Cancer Research UK (2023) it is predicted that its prevalence will rise by 74% in the UK by 2035. The international literature consistently suggests that the psychosocial quality of life of patients can be negatively affected by thyroid cancer (Sawka et al., 2009; Vega-Vasquez et al., 2015, McIntyre et al., 2018 Dionisi-Vici et al., 2021), although there is little explanation of the reasons for this. This is a longitudinal qualitative phenomenological study looking at the experience of diagnosis, treatment, recovery and follow-up.

AIM

The aim of the study was to explore the lived experiences of adults diagnosed with well-differentiated thyroid carcinoma and the factors that affect it.

METHOD

Study Design: Qualitative study, interpretivism paradigm, descriptive phenomenology.

Sample size: 25

Timeline: Longitudinal study. Eight patients were interviewed within eight weeks of diagnosis and were followed throughout their treatment journey (prospective longitudinal). The remaining 17 participants were interviewed retrospectively about the diagnosis, treatment and recovery from thyroid cancer (retrospective longitudinal)

Study Setting/recruitment: Participants were recruited from the Northern Centre for Cancer Centre at the Freeman Hospital (Newcastle upon Tyne NHS Foundation Trust), and from the charity Butterfly Thyroid Cancer Trust.

Sampling method: Convenience purposive sample

Inclusion/exclusion criteria: UK-based adult patients within 4 years of diagnosis with well-differentiated thyroid cancer.

Data collection

The primary data collection method was semi-structured in-depth interviews, a limited number of personal diaries were also used.

Data analysis

All interviews were recorded and translated verbatim. They were then coded using NVivo and analysed with Giorgi's descriptive phenomenological analysis and content analysis.

Ethics

The study received approval from Northumbria University Ethical Committee as well as HRA and NHS Ethics Committee.

RESULTS

Unmet needs	Participants voice	Recommendations
There are gaps in information provision, especially in psychological effects and support, long-term symptoms, and levothyroxine.	<i>They told me that it is slow growing, and I will be fine. They played it down a lot. I don't think they prepared me for all the side effects, apart from the trauma of the operation I was not ready and prepared for the symptoms and side effects. TC09</i>	Many people have no previous knowledge of thyroid cancer. Patients require thyroid cancer-specific information. It is important to make sure patients are educated on their new medication. Moreover, information about possible long-term symptoms and available support offered by the service providers or local charities should be provided.
The positive attitude of staff is essential in creating a positive experience, and negative interactions impact the experience negatively.	<i>But the registrar's attitude is probably something that stays with me as the most memorable thing out of the experience. She (oncology registrar) didn't ask me what I already know, which is like a cardinal sin as I am a healthcare professional, and from oncology you would expect excellent care, and she totally dismissed what I was going through with two small children. (...) I think it was just not handling that conversation well, she could have been more positive saying great survival rate etc., but she said it is just a touch of cancer etc. she didn't talk about any details. TC12</i>	Like all other patients, patients with thyroid cancer should be treated in a kind and compassionate manner at every interaction. Their diagnosis should not be looked at as a "good cancer".
Physical symptoms from treatment and during recovery disturb patients' daily lives. In addition, some of the side effects last for a long time.	<i>I still have not very good movement in my neck, and I still have scar pain, my thyroid nurse said it is because it was twice, I had that surgery twice, and because of the lack of movement and the feeling of it, I can't do the things that I wanted to do, and I think that affects how I am feeling. TC03</i>	The most common postoperative symptoms include pain, stiffness, tiredness, voice problems, swelling, and swallowing issues. Patients should be offered support with any issues they have, and referrals should be made when appropriate, especially if the symptoms persevere after the recovery period finishes.
Thyroid cancer diagnosis treatment and follow-up generate a lot of anxiety and worry that can last years after the treatment is completed.	<i>I scored maximum scores for anxiety and depression; off-the-scale depressed. They said they will refer to the GP. And then it will be months to get counselling. But surely, there has to be a psychologist within the oncology department. I didn't want to offload it to my wife, I wanted to do that with somebody else. TC04</i>	Treatment and Follow-up appointments, although appreciated by many, can induce anxiety. Follow-up is also an opportunity for any screening and referrals. Regular long-term screening, including physical and psychological complaints, should be a part of optimal care for thyroid cancer patients and survivors.
Reasons for not accessing support services- some were not interested, others were not offered support or the right kind of support (TC specific).	<i>I mean it is quite tricky because, in some ways it is like I am healthy and I don't really want to bother people, maybe they are busy dealing with people with more aggressive forms of thyroid cancer, I just kind of think I don't want to trouble them. NHS02int3</i>	It is important to encourage patients to seek support and access available support services.

CONCLUSIONS/RECOMMENDATIONS

The unmet needs for information and support identified by this study could be most effectively met if each centre providing care for thyroid cancer patients had a Thyroid Cancer Nurse Specialist or a named key worker for patients. This person would be in the best position to fulfil most information and support needs and to make referrals or referral suggestions to specialist services such as psychological therapies, physiotherapy, speech and language therapy and other public sector or charitable services.

REFERENCES

Cancer Research UK (2023) *Cancer Statistics, Cancer Research UK*. Available at: <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/thyroid-cancer/incidence#heading=Three>. (Accessed May 2023).

Dionisi-Vici, M. et al. (2021) 'Distress, anxiety, depression and unmet needs in thyroid cancer survivors: a longitudinal study', *Endocrine*, 74(3), pp. 603–610. Doi:10.1007/s12020-021-02786-y

McIntyre, C. et al. (2018) 'Quality of life in differentiated thyroid cancer', *International Journal of Surgery*, 50(July), pp. 133–136. doi: 10.1016/j.ijso.2017.12.014

Sawka, A. M., Goldstein, D. P., Brierley, J. D., Tsang R. W., Rotstein L., Ezzat S., et al (2009) 'The impact of thyroid cancer and post-surgical radioactive iodine treatment on the lives of thyroid cancer survivors: a qualitative study'. *PLoS One*, 4(1), e4191 Doi:10.1371/journal.pone.0004191. (Accessed: 15 January 2018).

Vega-Vázquez, M.A. et al. (2015) 'Quality of life-in patients with differentiated thyroid cancer at the general endocrinology clinics of the University Hospital of Puerto Rico', *Boletín de la Asociación Médica de Puerto Rico*, 107(1), pp. 25–31.

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