



Factors affecting lived experience of people with well-differentiated thyroid carcinoma in the UK.

A. Rogusz

University of Sunderland, Sunderland, UK.



AIM / OBJECTIVES

Although this cancer has a high survival rate, the quality of life of patients can be negatively affected (Dionisi-Vici, 2021) as much or more so than by more aggressive forms of cancer like colon, glioma or gynaecological cancer (Applewhite *et al.*, 2016). Existing studies are mainly quantitative and do not thoroughly explore the factors that impact people's experiences.

The **aim** of the project was: To explore the lived experiences of adults diagnosed with well-differentiated thyroid carcinoma and the factors that affect it. **Objectives:**

1. To use qualitative methods to explore the experiences of thyroid cancer patients – from diagnosis to recovery – from the patient's perspective.
2. To explore specifically the impact of hospital care and treatment.
3. Identify the most critical factors that positively and negatively affect the lived experience.
4. To make recommendations for improving practice in treating thyroid cancer patients

MATERIAL & METHODS

This is a qualitative phenomenological study looking at the lived experience of patients during and after their treatment for well-differentiated thyroid carcinoma.

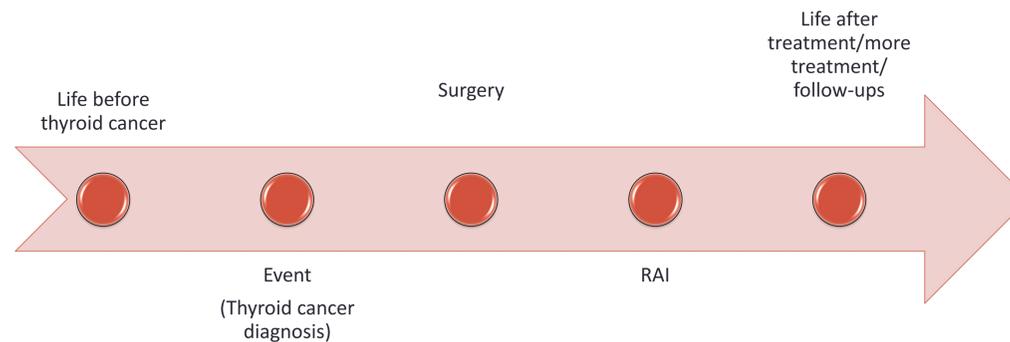
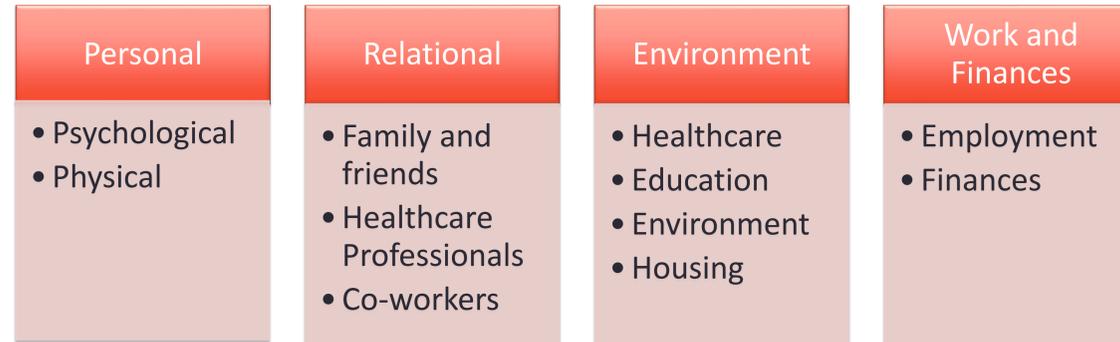
Twenty-five thyroid cancer patients, within four years of diagnosis, were recruited from the Northern Centre for Cancer Care at the Freeman Hospital, NHS, and from the charity Butterfly Thyroid Cancer Trust. Eight patients were interviewed within eight weeks of diagnosis and were followed throughout their treatment journey. The remaining 17 participants were interviewed retrospectively about the diagnosis, treatment, and recovery from thyroid cancer.

The primary data collection method was semi-structured in-depth interviews. All interviews were recorded and translated verbatim. They were then coded using NVivo and analysed with descriptive phenomenological analysis and content analysis.

RESULTS

- Demographically, most participants were female, working age, employed, married, had children and had no significant past medical history. Most participants were diagnosed with Papillary Thyroid cancer and had a total or partial thyroidectomy and RAI treatment.
- A framework of time-changing factors was designed. Life of participants may be affected by many different factors, and those factors may be very different between people. They also change over time. Some of the factors are more prominent during treatment, for example, short-lived side effects, and other factors affect people many months and years later, for example, long-term physical and psychological symptoms or financial strain.

Framework for factors affecting lived experience



Positive Factors:

- Well-informed at diagnosis
- Family supportive
- Partner supportive

Negative Factors:

- Distress waiting
- Not well informed
- Family not supportive or not present at diagnosis

Positive Factors:

- Positive experience with surgery
- No or little symptoms
- Positive experience of recovery

Negative factors

- Negative experience with surgery
- Postoperative symptoms
- Complications
- Work not supportive

Positive Factors:

- Positive experience with RAI
- No symptoms post RAI

Negative Factors

- Negative experience of RAI
- Isolation

Positive Factors:

- Happy with the scar
- No or few long-term symptoms
- Well informed
- improving psychological health

Negative Factors:

- Long-term symptoms
- Unhappy with scar
- long term work and finances affected
- Fatigue

RESULTS OF CONTENT ANALYSIS

POSITIVE FACTORS		NEGATIVE FACTORS	
having supportive family	23	long-term physical symptoms	21
happy with scar	23	other psychological symptoms	19
well informed	19	fatigue	19
partner supportive	19	post op physical symptoms	17
HCPs supportive	19	distressed waiting for treatment	13
positive experience of surgery	18	negative recovery	13
happy with monitoring	17	work affected	12
coping well	16	not coping well	11
friends supportive	15	some NHS complains	10
accessed charity support	15	finances affected	10
positive recovery	13	COVID negative experience	9
work not affected or very supportive	13	negative RAI	8
psychological health improves in time	12	negative experience of surgery	8
positive RAI	11	no charity support	8
no need for support	11	not well informed	7
no NHS complaints	11	no HCP support	6
psychological health ok	9	METS	5
feeling back to normal	9	not coming to terms	5
coming to terms	9	negative second surgery	4
COVID – ok experience	6	unhappy about monitoring	4
positive second surgery	5	SCAR negative	3
no fatigue	5	negative changes to fitness	3
positive changes in life	7	family not supportive	2
changes in fitness-positive	4	partner	1
		partner not supportive	1 not supportive, 4 singles

SUMMARY / CONCLUSION

The patient's psychological health, physical health, relationships, employment, and finances can be impaired by the diagnosis and treatment. Negative factors that affect the overall experience include physical side effects and psychological symptoms like distress during treatment and recovery. Isolation and loneliness can be one of major difficulties at many treatment stages, particularly when treated with radioactive iodine. Anxiety and fear were widespread among participants.

Experience with thyroid cancer can be very traumatic for thyroid cancer patients. Excellent medical and nursing care and supportive services are essential in providing optimal care for these patients. Despite the good prognosis, patients need emotional support and compassionate care as well as comprehensive, thyroid-cancer-specific information, referrals to specialist services and a thyroid cancer-knowledgeable key worker who can assess and address any unmet needs and support patients in navigating through the services.

References:

- Applewhite, M. *et al.* (2016) 'Quality of life in Thyroid Cancer in Similar to that of Other Cancers with Worse Survival', *World Journal of Surgery*, 40(3), pp. 551-561.
- 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.