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## DOCTORAL THESIS

### **Lived experience of people with thyroid cancer and factors that affect it: a phenomenology study**

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LIVED EXPERIENCE OF PEOPLE WITH  
THYROID CANCER AND FACTORS  
THAT AFFECT IT: A  
PHENOMENOLOGY STUDY

A E ROGUSZ

PhD

2022

# LIVED EXPERIENCE OF PEOPLE WITH THYROID CANCER AND FACTORS THAT AFFECT IT: A PHENOMENOLOGY STUDY.

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A thesis submitted in partial fulfilment of the requirements of the University of Northumbria at  
Newcastle for the degree of  
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Research undertaken in the Faculty of Arts, Design & Social Sciences and in collaboration with  
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upon Tyne

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## Abstract

### Introduction

Thyroid cancer is the most common thyroid neoplasia. It is a comparatively uncommon and low-mortality cancer. However, it is predicted that its prevalence will rise by 74% in the UK by 2035. The literature suggests that the psychosocial quality of life of patients can be negatively affected by thyroid cancer (Sawka *et al.*, 2009; Jeong *et al.*, 2015; Vega-Vasquez *et al.*, 2015), although there is little explanation of the reasons for this. Existing studies are mainly quantitative and do not thoroughly explore the factors that impact people's experiences.

### 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, 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.

### Findings

The diagnosis and treatment of thyroid cancer affect many aspects of patient's lives. Their psychological health, physical health, relationships, employment, and finances can be impaired. The exploration of hospital care and treatment yielded many important insights into the lived experiences of patients. Participants in this study had both positive and negative experiences of care and treatment. Factors that made the experience positive were compassionate and professional care from health care professionals, as well as having manageable physical side effects after surgery and during recovery. The opposite can impact the experience in a negative way. Isolation and loneliness can be major difficulties at many stages of treatment, particularly when being treated with radioactive iodine. Information provision is vital, but there were gaps in information that were identified by participants. These included possible long-term symptoms of treatment, practical information about levothyroxine and information about psychological support. Anxiety and fear were widespread among participants.

### Conclusion

The unmet needs for information and support identified by this study could be 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 a good position to fulfil most information and support needs and to make referrals to specialist services such as psychological therapies, physiotherapy, speech and language therapy and other public sector or charitable services.

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## **Author's Declaration**

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Any ethical clearance for the research presented in this commentary has been approved. Approval has been sought and granted through the researcher's submission to Northumbria University's Ethics Online System on 25/04/2019 and North East-Newcastle & North Tyneside 1 Research Ethics Committee (ref: 19/NE/0175).

**I declare that the Word Count of this thesis is 73 385**

Name: Alicja Elzbieta Rogusz

Signature:

Date: 1<sup>st</sup> August 2022

## Abbreviations

BTCT- Butterfly Thyroid Cancer Trust

CNS- Clinical Nurse Specialist

DoH- Department of Health

EBRT- External Beam Radiotherapy

FNA- Fine Needle Aspiration

FNAC- Fine Needle Aspiration Cytology

FTC-Follicular Thyroid Cancer

GP- General Practitioner

HCP-Health Care Professionals

HRQoL- Health-Related Quality of Life

MDT- Multidisciplinary Team

NHS- National Health Service

NICE- National Institute for Health and Care Excellence

NIHR- National Institute for Health Research

NUTH- Newcastle upon Tyne Hospitals Foundation Trust

PIS- Patient Information Sheet

PTC- Papillary Thyroid Cancer

QoL-Quality of Life

RAI-Radioactive Iodine Treatment

RAI-R- RAI Refractory

RRA- Radioactive Remnant Ablation

sTg- serum Thyroglobulin

TC-Thyroid Cancer

TC CNS- Thyroid Cancer Clinical Nurse Specialist

US- Ultrasound

TSH- Thyroid-Stimulating Hormone

WDTC- Well-Differentiated Thyroid Cancer

Well-TC- Wellbeing in Thyroid Cancer- abbreviation of the research project in this PhD thesis

WHO- World Health Organisation

## **Chapter 1 Introduction**

### **1.1 Overview of the chapter**

The purpose of this chapter is to provide a brief overview of Thyroid Cancer (TC) and the current management of the disease in the NHS. Furthermore, the scope of the problem that this research concentrates on is introduced. Finally, the study's justification is drawn, and future potential effects that may benefit patients, and health care providers are presented.

#### **Research aim**

To explore the lived experiences of adults diagnosed with well-differentiated thyroid carcinoma.

#### **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 lived experience.
4. To make recommendations for improving practice in treating thyroid cancer patients.

### **1.2 Thyroid Cancer**

#### **Thyroid gland**

The thyroid gland is a vital endocrine gland. It is involved in regulating metabolic processes (iciu, 2007). The gland produces three hormones: thyroxine (T3), triiodothyronine (T4) and calcitonin. T3 and T4 are responsible for the regulation of metabolism. The pituitary gland controls the thyroid gland, which is located in the brain. It produces a thyroid-stimulating hormone (TSH) that regulates the release of thyroid hormones (Rousset *et al.*, 2000). Pathology of the thyroid gland can be both benign and malignant. Thyroid nodules are widespread, and most are benign (Perros *et al.*, 2014). However, 10% of nodules are malignant (Poller, 2018). On palpation, thyroid nodules are present in 5% of women and 1% of men. However, on ultrasound, the results of screenings show that 50-70% of the population would have a thyroid nodule or nodules (Mitchell *et al.*, 2016). As seen above, thyroid nodules are common and, most of the time, benign.

## **Thyroid cancer statistics**

Thyroid cancer is relatively rare. Globally there were approximately 255,490 new cases in 2017 (Deng *et al.*, 2020). In the UK, there were 3,527 new cases of thyroid cancer a year between 2015 and 2017. There were 400 deaths between 2016 and 2018 in the UK. It is the 20th most common cancer type in men and the 17th in women (Cancer Research UK, 2017). Incidence in the UK is approximately five per 100,000 women and two men per 100,000 (Mitchell *et al.*, 2016). The reason it is more common in women is speculated, but a recent meta-analysis concluded that it is due to the changes in female hormones during the menstrual cycle and pregnancy (Mannathazhathu *et al.*, 2019).

According to the above statistics, it is a comparatively uncommon and low-mortality cancer. However, according to Cancer Research UK (2017), its prevalence has more than doubled since the 1990s (148% increase). It has risen by 80% in the last decade. It is predicted that it will rise by 74% in the UK by 2035. Globally, cases rose by 169% from 1990 to 2017 (Deng *et al.*, 2020). Thus, it is becoming more common. From the above statistics, the incidence is increasing, but the survival rate remains static, and mortality remains low.

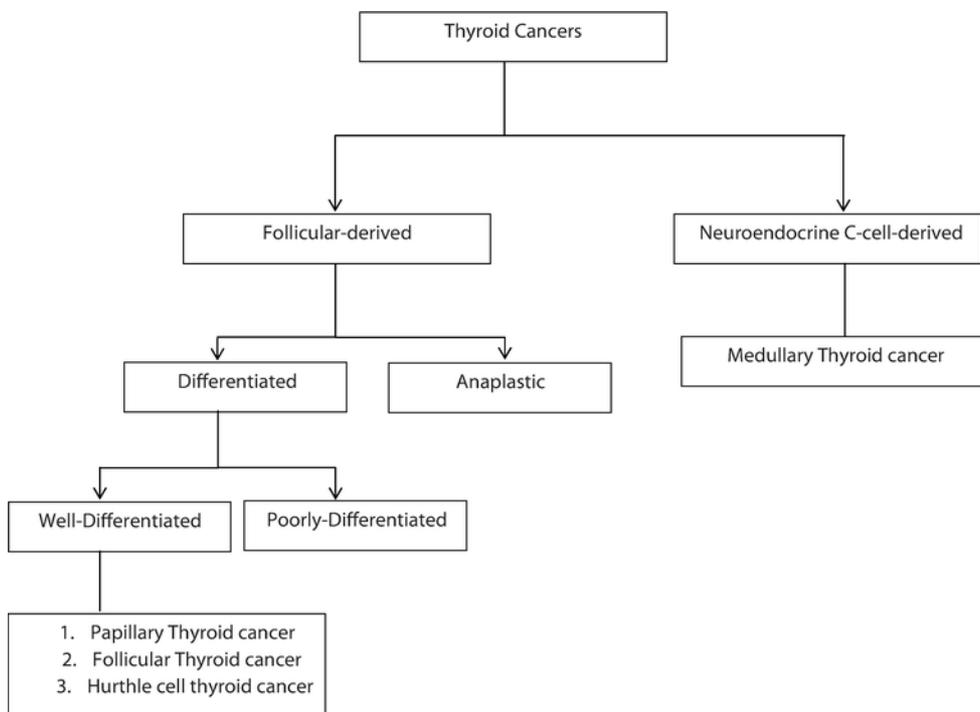
## **Causation**

It is speculated that the increasing numbers of thyroid cancer worldwide are related to factors like radiation and genetic and environmental factors (Piciu, 2017). For example, PCBs (Polychlorinated Biphenyls), BPA (Bisphenol A), phthalates, metals and metalloids are thought to cause disruption in thyroid function and promote the development of malignancy (Fiore *et al.*, 2019). Moreover, higher diagnosis rates may be due to improved access to health services and the development of medical imaging (Piciu, 2017). Risks factors for thyroid cancer include neck radiation in childhood, obesity, endemic goitre, Hashimoto's Thyroiditis, Cowden's Syndrome, family or personal history of thyroid adenoma, familiar thyroid cancer and familial adenomatous polyposis (Holm, Blomgren and Löwhagen, 1985; Preston-Martini *et al.*, 1987; Franceschi *et al.*, 1993; Thompson *et al.*, 1994; Ron *et al.*, 1995; Dal Maso *et al.*, 2000; Kitahara *et al.*, 2011).

## Different thyroid cancers

There are a few different types of thyroid cancer (Figure 1.1) with different histological characteristics. Different thyroid cancers include well-differentiated thyroid cancer, including papillary and follicular, poorly differentiated thyroid, anaplastic thyroid, and medullary thyroid cancer (Grimm, 2017). This thesis is about factors affecting lived experience of patients with well-differentiated thyroid cancer like Papillary Thyroid Cancer, Follicular and Hurthle (See Figure 1.1 below). The lived experience of patients with other types of thyroid cancer goes beyond the scope of this thesis.

**Figure 1.1 Classification of thyroid Cancer from (Khosravi *et al.*, 2017)**



## Differentiated Thyroid Cancer

Differentiated thyroid carcinomas include papillary and follicular carcinomas (Perros *et al.*, 2014). In patients with classical, well-differentiated thyroid cancer, very aggressive forms can be occasionally observed, making well-differentiated thyroid cancer, in some cases, unpredictable (Kaliszewski, 2019).

### **Papillary Thyroid Cancer**

Papillary thyroid carcinoma is the most common thyroid neoplasia. The cancer cells develop from the follicular epithelial cells (a type of cell within the thyroid gland) and have many variants, including, for example, classical, cystic and solid (Perros *et al.*, 2014). Papillary microcarcinoma is a tumour that measures up to 10mm in dimension. Papillary cancer has slightly better outcomes than follicular. However, survival rates are comparable when age and advancement at diagnosis are taken out of the equation (Donohue *et al.*, 1984). Within the PTC group, the poorer prognosis is associated with few histological types (different cells) (Kazaure, Roman and Sosa, 2012) and the degree of cellular differentiation (changes) and vascular invasion (how much blood supply is present) (Hay *et al.*, 1993).

### **Follicular Thyroid Cancer**

This cancer is also derived from the follicular epithelial cells. Follicular thyroid carcinoma has a few types, non-encapsulated or infiltrative, encapsulated, non-invasive, capsular and/or vascular invasion, diffuse/aggressive/multinodular (Perros *et al.*, 2014). In Europe, follicular TC occurs in 0.6-1.5/100 000 females and 0.2-0.8/100 000 males (Locati *et al.*, 2020).

### **Hurthle Cell Thyroid Cancer**

Hurthle Cell TC is a cancer type related to follicular cancer type. Poorly differentiated carcinomas are also correlated with a poorer outcome and the risk of recurrence and mortality. It is associated with the size of the primary tumour (Yang, Shen and Sakamoto, 2013). While FTC accounts for 10-20% of differentiated thyroid cancer, HCC accounts for 3% of differentiated thyroid cancer (Nilubol, Keutgen and Kebebew, 2017).

### **Medullary Thyroid Cancer**

This tumour develops from calcitonin-producing C thyroid cells. It is a sporadic disease and accounts for only 3% (adult) to 10% (paediatric) of thyroid cancers (Perros *et al.*, 2014). However, 25% of all cases are familial; hence genetic screening is essential (Mitchell *et al.*, 2016). The treatment for medullary thyroid cancer includes total thyroidectomy. Often neck dissection for the removal of lymph nodes is necessary. Radiotherapy and chemotherapy can be used in inoperable cases (Mitchell *et al.*, 2016). The prognosis is relatively good but much worse than differentiated thyroid cancer. The 10-year survival rate of medullary thyroid cancer is 65% (Htay *et al.*, 2017).

## Anaplastic Thyroid Cancer

Anaplastic carcinomas are sporadic. They are undifferentiated thyroid cancers. In Europe, The incidence is 0.1/100 000 for both men and women (Locati *et al.*, 2020). The prognosis for patients with anaplastic thyroid cancer is very poor (Janz *et al.*, 2019). Most patients present with a quickly growing thyroid mass in a long-standing goitre. Diagnosis is reached with fine needle aspiration or biopsy. Thyroidectomy can be used in small cancers. Treatments can include External Beam Radiotherapy and chemotherapy. However, palliative care is the leading management pathway for these patients (Mitchell *et al.*, 2016).

## Staging of well-differentiated thyroid cancers and survival statistics

Survival depends on the stage at which the cancer is detected (Verburg *et al.*, 2013)

Stage: 10-year survival (%):

1. 98.5
2. 98.8
3. 99.0
- 4a. 75.0
- 4b. 62.5
- 4c. 63

**Table 1.1 Thyroid cancer staging adapted from (Perros *et al.*, 2014, p. 5)**

<b>Thyroid cancer staging</b>
<b>Papillary or follicular thyroid tumours in a person younger than 45 years:</b>
<b>Stage I</b> describes a tumour with or without spread to lymph nodes and no distant metastasis.
<b>Stage II</b> describes a tumour with any metastasis regardless of whether it has spread to the lymph nodes.
<b>Papillary or follicular thyroid tumours in a person 45 years and older:</b>
<b>Stage I</b> describes any small tumour with no spread to lymph nodes and no metastasis.
<b>Stage II</b> describes a larger, non-invasive tumour with no spread to lymph nodes and no metastasis.
<b>Stage III</b> describes a tumour larger than 4 cm but contained in the thyroid with no spread to lymph nodes and no metastasis. Alternatively, any localised tumour spread to the lymph nodes' central compartment, but no distant spread.

**Stage IVA:** This stage describes a tumour that has spread to nearby structures, regardless of whether it has spread to the lymph nodes but has not spread to distant places. Or this describes a localised tumour, with lymph nodes spread beyond the central compartment, but no distant spread

**Stage IVB** describes a tumour that has spread beyond nearby structures, regardless of spread to lymph nodes, but no distant spread.

**Stage IVC:** This stage describes all tumours with evidence of metastasis.

The long-term prognosis for well-differentiated thyroid cancer is excellent, especially in the early stages. Adult survival rates range between 92-98 % at the 10-year mark. Factors influencing prognosis include age at diagnosis, gender, histology characteristics and tumour stage. In addition, a few factors affect the prognosis of death and recurrence. Age is shown as one of these factors. The risk of death increases with age, especially over 40 (Akslen *et al.*, 1991) and males (Yang, Shen and Sakamoto, 2013).

Nonetheless, the mortality rate increases steadily from 40–45 years (Akslen *et al.*, 1991). Other factors associated with an increased likelihood of malignancy are a hard node on palpation, fast-growing nodule, vocal cord paralysis, fixation to nearby structures, family history of thyroid cancer, the history of neck radiation and regional lymphadenopathy (enlargement of lymph nodes) (Kumar *et al.*, 1999). The most critical conditions to maintain a good prognosis are accurate diagnosis, appropriate treatment, and long-term regular follow-up (Mitchell *et al.*, 2016; Gillanders and O’Neill, 2018).

### **Recurrent, persistent disease and metastases**

Between 5 to 20 % of patients develop recurrence, either local or regional, that needs more treatment (Mitchell *et al.*, 2016). Early detection and management of recurrent disease provide long-term survival and cure (Perros *et al.*, 2014). Recurrence is usually managed with additional surgery and/or RAI therapy. Local lymph node metastases are relatively common and affect overall prognosis (Yang, Shen and Sakamoto, 2013). The incidents depend on the intensity of the investigation (Perros *et al.*, 2014). Distant metastases occur in 5–23% of cases (Perros *et al.*, 2014), 10-15% (Mitchell *et al.*, 2016) in patients with differentiated thyroid cancer, most of the time in the lungs and bones (Perros *et al.*, 2014). Metastases can develop decades after initial treatment. Patients with a history of thyroid cancer are at a higher risk of developing different forms of cancer, especially those with micropapillary cancer (Endo *et al.*, 2018).

In the case of RAI-R (radioiodine refractory thyroid cancer is a thyroid cancer that does not react to radioactive iodine anymore), the 10-year survival rate drops dramatically to only 10%

(Durante *et al.*, 2006). Treatment for RAI-refractory thyroid cancer is limited, but research is ongoing to produce a new effective treatment (Gallop *et al.*, 2015).

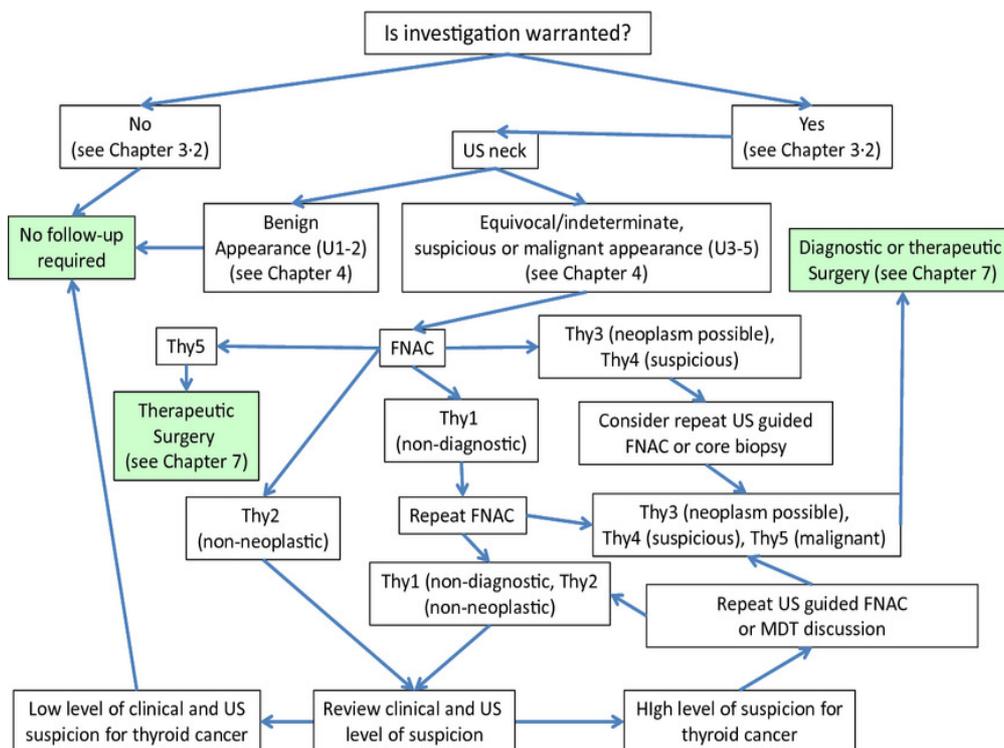
### Thyroid cancer in a paediatric population

Thyroid nodules found in children are more likely to be aggressive than in adults (de Jong *et al.*, 2021). Moreover, children under 10 years old are at increased risk of recurrence compared to older people (Akslen *et al.*, 1991; Oyer, Smith and Lentsch, 2012). Papillary cancer in children is also more malignant than in adults, and the prevalence of lymph node involvement is up to 90% (Paulson, Rudzinski and Hawkins, 2019). Nonetheless, they are rare (de Jong *et al.*, 2021). Follicular cancer in children is also sporadic, and the outcomes are like adult patients (Papini *et al.*, 2002).

### 1.3 Thyroid cancer management – Current clinical pathway in the National Health Service in the UK.

Figure 1.2 below presents a clinical decision-making flowchart. The clinical decision-making in thyroid cancer is complicated and multi-step; it often takes a long time to reach and confirm the diagnosis (Perros *et al.*, 2014).

**Figure 1.2 Investigation and management of thyroid nodules** (Perros *et al.*, 2014)



## **Personalised decision making**

Personalised decision-making is critical in the management of thyroid cancer. The treatment decisions usually happen within an MDT meeting, and the conclusions are discussed with patients to involve them in the decision-making. Members of the MDT include an endocrinologist, oncologist, surgeon, nuclear medicine doctor, TCCNS and members of other supportive services. In order to conclude the treatment decision, the benefits and detrimental effects are considered, including considerations of age, size of the tumour, characteristic, localisation, extrathyroidal involvement and other clinical, histopathological parameters and patient's situation and state of health (Perros *et al.*, 2014; Mallick *et al.*, 2018).

## **Presentation and referral**

Most thyroid cancer nodules are first presented in primary care or are discovered accidentally during other investigations. Then a referral to cancer services should be made by the General Practitioner (GP). There can be urgent and non-urgent referrals depending on the presentation. With an urgent referral, patients should be seen within two weeks, according to the Department of Health Cancer plan document (Department of Health, 2006). Symptoms warranting emergency referral include patients presenting with compromised airways and stridor (difficulty breathing) that is associated with a thyroid nodule or goitre. Symptoms requiring urgent GP referral include patients with a change in their voice or hoarseness that is associated with a thyroid nodule or thyroid goitre, individuals with cervical lymphadenopathy (swelling of lymph nodes), children with nodules, or a thyroid mass that is growing fast warrant emergency referral (Mitchell *et al.*, 2016). In addition, patients may undergo various clinical examinations, including examination of the vocal cords with an endoscope, neck and lymph nodes palpation, blood test, ultrasound (US) and biopsy (Mitchell *et al.*, 2016).

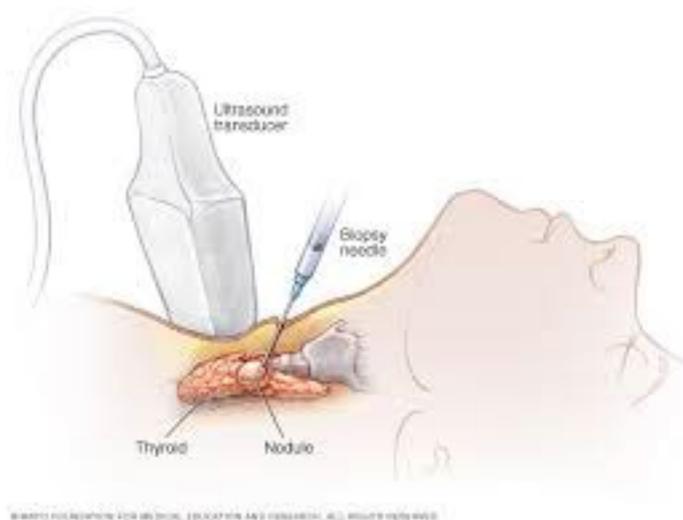
## **Ultrasound assessment of nodules**

Although there may be other assessments required, ultrasound is an examination everyone suspected of having thyroid cancer must go through. Specific features of a nodule or a nodule in question may point to either a benign nodule, indeterminate, suspicious or malignancy (Perros *et al.*, 2014). Ultrasound use is very beneficial in the investigation of suspicious nodules. The results help further clinical decision-making, for example, a decision to perform FNA (Fine Needle Aspiration). This procedure can rule out thyroid cancer. Hence ultrasound-guided FNA increases the accuracy of findings and improves the diagnostic process (Mitchell *et al.*, 2016).

## Biopsy - Fine Needle Aspiration

Fine Needle Aspiration Cytology is an essential and economic examination for suspicious thyroid nodules under a microscope. The results of FNAC determine further treatment; results can be non-diagnostic (Thy1), benign (non-neoplastic) (Thy2), neoplasm possible (Thy3), and suspicious (Thy4) and malignant (Thy5). The results can reassure the patient about the benign character of the nodule or triage patients for diagnostic or therapeutic surgery depending on the results (Perros *et al.*, 2014). The procedure usually takes place in an outpatient clinic. A very fine needle is inserted into the nodule, and a sample is removed (see Figure 1.3). However, it cannot diagnose follicular thyroid cancer (Perros *et al.*, 2014).

**Figure 1.3 Fine Needle Aspiration of Thyroid Nodules. Available at <https://www.mayoclinic.org/diseases-conditions/thyroid-cancer/diagnosis-treatment/drc-20354167>**



## Surgery

In the case of Papillary Thyroid Cancer, thyroid surgery for diagnostic purposes is appropriate for patients with Thy3 results from FNAC. In these cases, hemithyroidectomy is used. Hemithyroidectomy is a surgical procedure where half of the thyroid gland is removed. Some patients with Thy3 require total thyroidectomy, depending on other clinical features. The histopathological results from the diagnostic hemithyroidectomy determine if there is a need for other therapeutic surgery to remove the remaining half of the thyroid. Therapeutic thyroid surgery is surgery performed for Thy4 results. If the tumour is small, then hemithyroidectomy may be appropriate. However, in many cases, a total thyroidectomy is performed. Total thyroidectomy is associated with a lower recurrence rate and improved survival (Mitchell *et al.*, 2016).

The situation with Follicular Thyroid Cancer differs. Most patients going through surgery for follicular thyroid cancer will be diagnosed after their surgery. The reason for this is that the histology result cannot currently, in a reliable way, differentiate benign follicular lesions from follicular thyroid cancer. Therefore, low-risk follicular cancer that is less than 4cm and is not invasive can be treated by hemithyroidectomy without further treatment. However, Hurthle cell cancers are more aggressive and total thyroidectomy is more appropriate (Mitchell *et al.*, 2016).

The parathyroid is a gland that lies close to the thyroid gland. It is not related to the thyroid but during thyroidectomy, parathyroid glands may be accidentally removed or damaged as it is challenging to distinguish the parathyroid gland from thyroid tissue and the surrounding tissue (De Leeuw *et al.*, 2016). This is because they are of small size and variable location.

Parathyroids produce a parathyroid hormone which regulates calcium, phosphate and magnesium function. Sometimes thyroid cancer patients need to take calcium supplements for the rest of their lives as hypocalcaemia may produce a range of symptoms (Perros *et al.*, 2014). Although thyroidectomy is a safe operation (Koyuncu *et al.*, 2003), it has been noted that in 6.4% to 31% of cases, during thyroidectomy, incidental parathyroidectomy is performed (Erbil *et al.*, 2009). Moreover, parathyroid glands are supplied by thyroid arteries. Therefore, it is essential to consider this when performing a thyroidectomy (Sakorafas *et al.*, 2005).

### **Radioactive Iodine (RAI) therapy for Differentiated Thyroid Cancer**

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. However, a diet rich in iodine can compromise the effectiveness of the treatment. Hence patients are advised to follow a low-iodine diet 1-2 weeks before the treatment. Patients undergoing radioactive iodine treatment must be admitted to the hospital for up to 5 days. The hospital stay is in isolation due to the radiation risk to other people. The patient is confined in a treatment suite and is given a radioactive iodine tablet by members of the nuclear medicine department. When their radiation measurements return to safe levels, patients are allowed to leave the hospital, but sometimes some restrictions are still necessary, for example, staying away from children or pregnant women (Perros *et al.*, 2014).

### **Immediate follow-up**

A clinical assessment of the neck is performed during an immediate routine follow-up. Any abnormalities lead to further examinations. Serum thyroglobulin (sTg) measurement and a whole body scan and ultrasound of the neck are performed 9-12 months after RAI. In most

cases, the levels will decrease, and another sTg test is recommended every 12 months. If sTg is still present, this could mean residual/recurrent cancer is present, but most of the time, it signifies the presence of remaining thyroid tissue. Further evaluation is necessary if the levels are persistent (Perros *et al.*, 2014).

### **Long-term follow-up**

Lifelong follow-up for patients who received treatment for differentiated thyroid cancer is recommended because thyroid cancer can return even a long time after initial treatment. Moreover, the side effects of long-term TSH suppression (discussed in chapter 2) and late effects of iodine treatments are also monitored. The frequency depends on dynamic risk stratification, a clinical decision tool (Perros *et al.*, 2014).

During follow-up appointments, a history is taken, and a clinical examination is performed. Other investigations include Tg determination (serum thyroglobulin-thyroid cancer marker), calcium monitoring when required, and ultrasound (Mitchell *et al.*, 2016). Most patients are followed up in a nurse-led clinic, and the follow-up schedule depends on the level of risk. For example, after hemithyroidectomy, patients do not require TSH suppression. Hence they may have less frequent monitoring visits (Perros *et al.*, 2014).

### **Lifelong thyroid hormone replacement therapy**

Thyroid hormone therapy is one of the significant elements of post-treatment management of thyroid cancer. It is necessary to replace the hormone that the thyroid gland was producing as it is necessary for body functioning. The replacement is needed for all patients who underwent total thyroidectomy and about half of those who had hemithyroidectomy. The appropriate dose can be challenging to establish and sometimes takes time. Thyroid hormone replacement therapy aims at restoring normal serum levels of thyroid hormones. The suppression of TSH happens when serum TSH results are below the lower limit. The reason is to slow thyroid cancer cells' potential growth and spread. Radioiodine uptake is very low when patients are on suppressive hormone doses. Because of that, levothyroxine must be withdrawn for several weeks before radioiodine therapy is administered; alternatively, rhTSH (recombinant human TSH) can be used. It is used in most cases nowadays, which is crucial for patients as they avoid the symptoms of levothyroxine withdrawal (Grani *et al.*, 2019).

## **Other treatments**

As stated above, despite a good prognosis, some people suffer from persistent disease or metastases. In those cases, chemotherapy and other targeted therapies are used, including arotrectinib, vemurafenib, sunitinib, sorafenib, selumetinib, and axitinib (Khatami *et al.*, 2019).

## **Palliative care**

Palliative management is rarely needed. Chemotherapy is considered in patients with quickly advancing cancer, RAI-R refractory, metastatic disease, and locally advanced disease and if targeted therapies are unavailable or unsuccessful. Apart from the above-listed treatments, Palliative EBRT (External Beam Radiation Therapy) can be used for localised treatment. Surgery, laser, radiofrequency ablation and stents can alleviate distressing palliative symptoms like stridor (difficulty breathing) (Perros *et al.*, 2014).

## **New trends in treatment**

New trends in modern treatment that are relevant to this study (excluding new pharmacological treatments and trials as this goes beyond the scope of this thesis) include:

- Using a less aggressive, more conservative approach to treatment, more monitoring using the US instead of radical surgeries
- Person-centred individualistic clinical decision-making by multidisciplinary teams in cooperation with patients
- Inclusion of patients in decision-making (Mallick *et al.*, 2018)

This new approach aims to improve patient survival, reduce the recurrence rate and protect patients' quality of life.

There is a recent recognition of overdiagnosis and a push for more conservative management of low-risk papillary thyroid cancer (PTC). More conservative management would include less extensive surgery and holding off on RAI treatment. It promotes using active surveillance as an alternative for many low-risk patients. Moreover, risks to the quality of life should always be considered when making clinical decisions about treatment (Krajewska *et al.*, 2020; Lohia *et al.*, 2020). NICE guidelines are being developed with heavy input from patient representatives,

including the BTCT charity. The expected publication date is the 16th of November 2022 (*Thyroid cancer: assessment and management In development [GID-NG10150]*, no date). NICE is a public body of the Department of Health and is responsible for designing health and social care guidelines. If the new guidelines also lean more towards more conservative management and active surveillance (which is strongly expected), patients' quality of life would be protected. However, other issues could arise, for example, fear of advancement of cancer or recurrence. Moreover, some patients still could prefer more radical management. Thus, management decisions should be made individually, and patients should receive robust counselling regarding their options.

### **Clinical Nurse Specialist role**

Clinical Nurse Specialists are vital in managing thyroid cancer in the UK. It is recognised in the literature that CNS plays a pivotal role in managing many diseases (Fulton, Lyon and Goudreau, 2020; Ulit *et al.*, 2020; Leary, 2021). In thyroid cancer specifically, CNSs support coordinating a multidisciplinary treatment plan. They provide information, support, follow-up care, and screening for any psychological impairments. They can initiate referral processes to assist patients with their physical and emotional struggles if necessary. They can also support patients in making informed decisions (Kendell and Armstrong, 2018). The Cochrane review concluded that psychosocial nurse-led interventions could improve mood in recently diagnosed oncological patients (Galway *et al.*, 2012).

Not every NHS trust has a nurse specialising in thyroid cancer. Their role and care plans may also vary from trust to trust. In order to identify any concerns that patients have, the TCCNS in NUTH uses a Concern Checklist designed by Macmillan Cancer Support. It is a long list of concerns from different areas of life. It takes place at diagnosis, one week following diagnosis at a holistic needs telephone appointment, two months post RAI, then at dynamic risk stratification and again in the case of recurrence. It helps identify any support needs that people may have.

There is no national standard procedure for screening thyroid cancer patients' quality of life. Different clinics use different methods. The practice of screening for the emotional side of cancer is highly varied, with patients asked to fill in questionnaires at various stages of the treatment in various clinical settings. Screening tools' utility and validity have been questioned (Salmon *et al.*, 2015).

## **Butterfly Thyroid Cancer Trust (BTCT) support**

The Butterfly Thyroid Cancer Trust is a multi-award-winning organisation created to support patients with thyroid cancer. This registered charity provides many services, including ‘The Butterfly Model’ support service that collaborates closely with the Northern Centre for Cancer Care in Newcastle upon Tyne. It provides on-site person-to-person support from thyroid cancer survivors to newly diagnosed cancer patients. This service has been provided for many years and has received positive patient feedback. There is also a ‘buddy system’ where a trained cancer survivor provides support. In addition, the charity provides a help-line for patients and has created information packs containing extensive thyroid cancer-specific information for patients. The charity also finances the national modernization of radiation suites to improve the environment in which patients spend their isolation during radiation treatment (Farnell, Bliss and Mallick, 2018).

### **1.4 The scope of the problem**

Patients diagnosed with thyroid cancer can experience significantly decreased quality of life (Bârbuş *et al.*, 2017; Dionisi-Vici *et al.*, 2021). Thyroid cancer has a high survival rate but also a high recurrence rate and patients in most cases will have lifelong follow-ups. Most current literature about patients' experience with thyroid cancer is constructed from quantitative studies measuring patients' quality of life. These researchers used quality-of-life questionnaires, apart from (Sawka *et al.*, 2009), who used focus groups to explore the impact of thyroid cancer on quality of life. Other qualitative studies concentrate on specific aspects of the experience but do not provide a holistic exploration of the experience.

Studies comparing the quality of life of thyroid cancer patients and people with other cancers show that thyroid cancer has an equal or worse impact on quality of life (Applewhite, White, *et al.*, 2016), despite high survival rates and a good prognosis. Thus, there is a lack of qualitative evidence and a lack of proposed explanation for decreased quality of life. This research into a lived experience can help clinicians to address these issues and develop interventions that would support patients through thyroid cancer diagnosis, treatment and long-term survival. It is supported by literature that more qualitative research is needed to define the unmet needs of patients with thyroid cancer and to identify interventions with evidence-based benefits (Duan *et al.*, 2015; Gamperet *et al.*, 2015; Morley and Goldfarb, 2015). Thus, this highlights the importance of justification for this study.

In order to conduct valuable research with the potential to help patients directly, the researcher explored lived experience and highlighted factors that affected that experience, according to participants. In this study, the researcher looked at factors across all areas of life that may affect lived experiences following thyroid cancer diagnosis and not only health-related factors like most other studies. Furthermore, the researcher chooses a phenomenological approach to explore the lived experience and establish the main issues faced by people in this situation. The researcher believes this approach gives an in-depth understanding of the effect of disease on people's lives. As a result, it contributes uniquely to the body of knowledge surrounding living with thyroid cancer. It can also help promote understanding of why the quality of life of people with thyroid cancer is comparable to those affected by other cancers that have much lower chances of recovery and survival, as well as having more intrusive treatment protocols.

### **1.5 Justification of the research study. The future benefits for NHS and patients**

Publicly, there have been a lot of individual, very moving accounts, for example that of Jane Tomlinson, but less work that seeks to establish common themes in patients' experiences through qualitative research. This study can improve our understanding of the lived experience of living with his disease. It fills in a significant gap in current knowledge. Knowledge of the lives of cancer patients enables professionals to understand the complexity and challenges of living with cancer (Cella and Stone, 2015) and enables them to provide person-centred care. Person-centred care should be practised at all levels of healthcare (Byrne, Baldwin and Harvey, 2020). The results may be used to improve the services provided for patients and improve understanding amongst health care professionals and charities about patients' needs with potential long-term benefits for patients. Health care providers can then, in turn, educate patients on how to deal with challenges and symptoms, support patients and refer them to appropriate services when necessary (Huang *et al.*, 2004), as well as support healing and encourage access to resources (Easley, Miedema and Robinson, 2013).

It is important to note that research into the lived experience of patients with cancer falls into the scope of the large-scale NHS Long-Term Plan (NHS, 2019). An additional £20.5bn was promised to support the struggling NHS and develop more streamlined services. One of the plans aims is to support and improve cancer services (among other goals, including improving long-term conditions and enhancing preventative care).

This knowledge can also assist clinicians and researchers in concentrating their intervention development and research on those central issues. This research also provides a list of

recommendations for practice and support services based on participants' descriptions of phenomena. In addition, knowledge about their needs and proposed solutions were generated. This study was designed to provide the funding charity BCTC practical information about lived experience and unmet needs. This will assist this national charity in supporting patients. The main potential impact is improving patients' experiences with thyroid cancer and providing directions for future research within the NHS.

## Chapter 2 Literature Review

### 2.1 Introduction

This chapter is a scoping literature review regarding experiences of diagnosis, treatment, and recovery from thyroid cancer. Although this thesis uses the concept of *lived experience*, most literature on the topic uses the term *quality of life*. ‘Quality of life is an intangible, subjective perception of own lived experience’ (Plummer and Molzahn, 2009, p. 140). Both concepts can be used to describe the experience and the effect of the experience on people’s lives. Those studies were included. Quality of life is a term that relates to lived experience as it considers participants’ perceptions of their life. The author wanted to provide depth to what was previously known as a tick-box on a questionnaire. In-depth interviews facilitate very personal conversations that produced a detailed, personal account of the lived experiences of thyroid cancer and how it affected people’s lives.

Initially, the overall results of studies looking at the impact of thyroid cancer on quality of life are discussed in this review. It is interesting as the results of studies were varied and sometimes contradictory. Next, a comparison between the general public and people with other types of cancer is presented. Then, the literature on the experiences of treatment phases and different treatment options is presented. Following that, physical and psychological health is considered. In this subsection, more and less common symptoms are discussed. Then, factors affecting the lived experiences of people with thyroid cancer are presented, including relationships with friends, family, and health care providers. Finally, in this section, the author discusses the impact of factors like finances and work.

### 2.2 Scoping literature review process

Presented below is a scoping literature review. A literature review is an ‘analysis, critical evaluation and synthesis of existing knowledge relevant to your research problem. (...)’ (Hart, 2018, p.3). A literature review is used to find out what is already known about the topic and identify issues worth addressing. It explores the breadth and depth of the literature gathered from heterogenic sources (Thomas *et al.*, 2019) which could include research and not research sources, for example, policy (Peters *et al.*, 2020). This approach was taken because the researcher intended to find out information from variety of perspective that would not be possible if a focused, systematic literature review had been taken. The main advantage of scoping review is ‘its ability to extract the essence of a diverse body of evidence and give meaning and significance to the topic’ (Davis *et al.*, 2009, pp. 1398). The framework for

scoping literature review is presented by (Arksey and O'Malley, 2007) and includes six stages: identifying the research question, identifying the relevant studies, study selection, charting the data, summarising and optional consultation stage.

*Identify the relevant studies*

Most popular health-related databases were used to search for the literature. They can be seen in Table 2.1 below. Search terms and Boolean operators that were used are presented in table 2.2.

**Table 2.1 List of databases searched**

1	Northumbria University Library search engine
2	(CINAHL) Cumulative Index to Nursing and Allied Health Literature
3	Google Scholar
4	Medline/Pubmed
5	BMJ Publishing Group
6	MEDLINE
7	Health Research Premium Collection
8	Scopus

**Table. 2.2 Search Strategy for Scoping Literature Review**

Search Terms 1	Boolean operators	Search Terms 2
/or/ Thyroid cancer/carcinoma/Papillary cancer/ Follicular/ Differentiated	And	/or/ Experience, quality of life, wellbeing, wellness, happiness, mental health, hospital care, nursing care, medical care, distress, anxiety, psychological health
Thyroidectomy /or/ hemithyroidectomy	And	/or/ Experience, quality of life, wellbeing, wellness, happiness, mental health, hospital care, nursing care, medical care, distress, anxiety, psychological health
Radioactive Iodine Ablation and variations RAI /or/ radioactive iodine treatment	And	/or/ Experience, quality of life, wellbeing, wellness, happiness, mental health, loneliness, hospital care, nursing care, medical care, distress, anxiety, psychological health

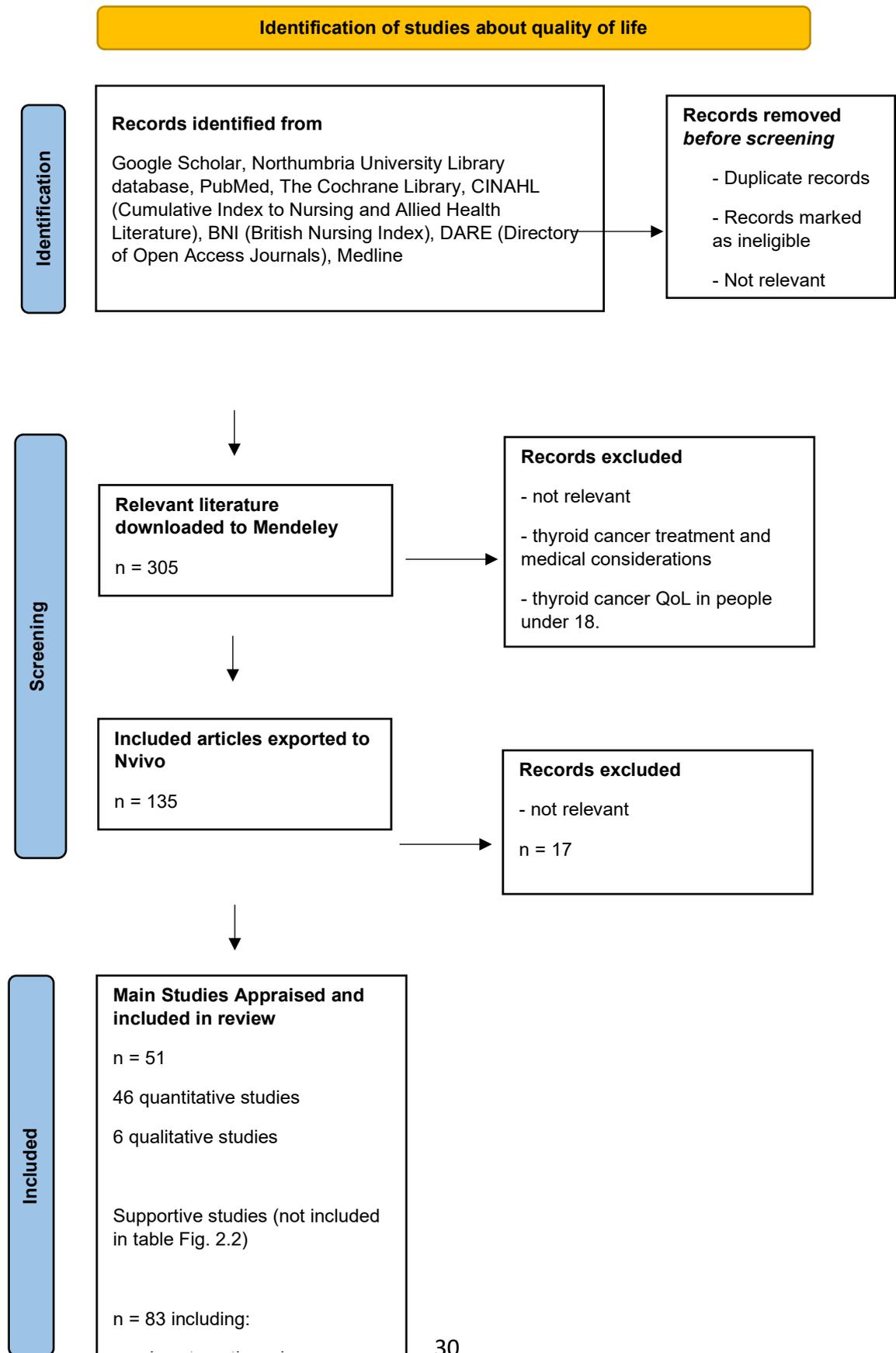
### Study Selection

The inclusion and exclusion criteria for scoping reviews are more flexible when compared to systematic reviews (Davis *et al.*, 2009). This literature review is based mainly on primary sources. However, due to the scoping nature of this review, other sources like review articles were included in the discussions. The process of elimination is shown in Fig. 2.3. This process is an example of the process used in this scoping review, as it only shows studies about quality of life in thyroid cancer. Some studies concentrated on particular aspects of quality of life, while others looked at the overall quality of life measured using various tools. Other studies looked at treatment experiences regarding psychological distress and physical symptoms. Out of the studies looking at precisely quality of life in thyroid cancer, the vast majority of the available literature presents the results of quantitative studies (46) and only six sources use qualitative data.

**Table 2.3 Inclusion and exclusion criteria for scoping review**

	<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>
<b>Publication Type</b>	Peer review journals, conference posters/abstracts	Any not subject to peer-review
<b>Study Type</b>	Qualitative Quantitative and mixed methods primary studies	Reviews, expert opinions, single case reports
<b>Population</b>	Adults diagnosed with well-differentiated thyroid carcinoma and survivors	Children, anaplastic thyroid cancer, terminal cancer
<b>Outcomes</b>	Experience, quality of life, wellbeing, wellness, happiness, mental health, hospital care, nursing care, medical care, distress, anxiety, and psychological health.	Treatment options, pharmacology, radiation.

**Fig. 2.1 Adapted From Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, *et al.* The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372: n71. DOI: 10.1136/BMJ.n71**



### *Charting the data and summarising*

The primary literature search was performed in October 2019. All identified articles were downloaded to Mendeley for further review. All selected articles for the literature review were uploaded to the NVivo program. NVivo is software that can be used to synthesise written information (Harding, 2019). Then they were read in detail and coded. The initial nodes were then categorized. The main categories are quality of life, the experience of having thyroid cancer, information provision and involvement in decision making, the physical and psychological effect of thyroid cancer, the impact of TC on relationships with family, friends and HCP, the effect of TC on finances and work. Supplementary searches were performed in August 2021 to find any newly-released, relevant articles. Sixteen new primary quantitative articles were found. No qualitative research was found to be added to the review. All new articles were reviewed for relevant information manually without using NVivo software. The critical appraisal of major articles can be found in Appendix 1 on page 190.

## **2.3 Quality of life of thyroid cancer patients**

### **2.3.1 Quality of life as a subjective perspective of own lived experience**

In health studies, researchers often choose the concept of *quality of life*. Quality of life results from a person's situation, beliefs and values. (Cohen *et al.*, 1996) noted that quality of life is essential to people. It is a term used frequently in healthcare in the context of effects of illness, for example, quality of life in chronic fatigue (Schweitzer *et al.*, 1995) or older age (Boggatz, 2016). It is also used in studies evaluating the impact of treatment on people's lives (Mason *et al.*, 2018). Quality of life is a common concept of interest in nursing research and theory (Plummer and Molzahn, 2009; Wu and Harden, 2015). Achieving good quality of life is a goal of nursing. By understanding people's quality of life, nurses can honour their patients' lived experiences (Parse, 1996). Quality of life is a term that relates to lived experience as it considers participants' perceptions of their life.

Adverse life events can affect the quality of life, sometimes called critical moments (Thomson *et al.*, 2002). Such events include bereavement, divorce or ill health (Cieslik, 2015). In addition, significant life events like marriage breakdown or unemployment significantly impact people's lives. These changes in circumstances can be long-term (Luhmann and Intelisano, 2018). According to (Anusic, Yap and Lucas, 2014), people do not fully adapt to some changes in their lives. Moreover, even if circumstances change for the better again, level of life quality of people

may not go back to normal (Diener, Lucas and Scollon, 2006).

### **Quality of life in thyroid cancer**

In recent years there has been an increase in studies on the quality of life in different cancers (Bărbuş *et al.*, 2017). However, the quality of life in patients with thyroid cancer is rarely measured. Expert clinicians suggest that it is because those patients appear to be well and have a good prognosis (Duan *et al.*, 2015). Studies comparing the quality of life of thyroid cancer patients and people with other cancers show that thyroid cancer has an equal or worse impact on their quality of life (Applewhite, White, *et al.*, 2016), despite high survival rates and an excellent prognosis. Possible reasons are that thyroid cancer patients have to go for regular follow-ups for the rest of their lives (Lubitz *et al.*, 2017), and they experience ongoing fear of recurrence (Rogers *et al.*, 2017) even many years after the cure (Hedman, Djärv, *et al.*, 2017). Thyroid cancer can be unpredictable (Kaliszewski, 2019) and can return even after many years have passed from initial treatment.

### **2.3.2 General Results and Comparison with the general public**

The negative impact of cancer on the quality of life in oncological patients has been well established by previous research (Ferreira *et al.*, 2019; Fernández de Larrea-Baz *et al.*, 2020). Although thyroid cancer has a high survival rate, most authors would agree that the quality of life of patients can be negatively affected (Schultz, Stava and Vassilopoulou-Sellin, 2003; Tagay *et al.*, 2006; Hoftijzer *et al.*, 2008; Sawka *et al.*, 2009; Ying *et al.*, 2009; Husson *et al.*, 2011; Costa and Pakenham, 2012; Aschebrook-Kilfoy *et al.*, 2015; Gamperet *et al.*, 2015; Grogan, Aschebrook-Kilfoy and Angelos, 2016; Singer *et al.*, 2016; Hedman, Djärv, *et al.*, 2017; McIntyre *et al.*, 2018a). Furthermore, psychological wellbeing, as well as the quality of life, can be strongly influenced by the diagnosis of thyroid cancer and be decreased when compared to the healthy population (Schultz, Stava and Vassilopoulou-Sellin, 2003; Roberts, Lepore and Urken, 2008; Ying *et al.*, 2009; Husson *et al.*, 2011; Easley, Miedema and Robinson, 2013; Roerink *et al.*, 2013; Buchmann *et al.*, 2015; Gamperet *et al.*, 2015; Gallop *et al.*, 2015; Lubitz *et al.*, 2017; Rogers *et al.*, 2017). Although, some decline in quality of life was also reported by the control group (Pelttari *et al.*, 2009). Besides psychological issues like anxiety, social functioning seems strongly affected (Botella-Carretero *et al.*, 2003; Hoftijzer *et al.*, 2008; Lee *et al.*, 2010; Aschebrook-Kilfoy *et al.*, 2015; Lubitz *et al.*, 2017). Moreover, when comparing the quality of life in patients with recurrence/persistence against people with localized disease, multiple survey results showed significant differences between the pre-operative and postoperative quality of life (Lubitz *et al.*, 2017). Furthermore, patients with metastasis from

thyroid cancer had significantly impacted their quality of life (Haraj *et al.*, 2019).

On the contrary, some authors take the position that there are no significant differences in total HRQoL (Health-Related Quality of Life) scores between thyroid cancer survivors and the age-standardised general population (Crevenna *et al.*, 2003; Peltari *et al.*, 2009; Husson *et al.*, 2011; Vega-Vázquez *et al.*, 2015; Metallo *et al.*, 2016; Hossain, Islam and Khatun, 2019; Massimo Giusti *et al.*, 2020). The study by Vega-Vázquez *et al.* (2015) concluded that quality of life is minimally affected. The authors did not find any association between type of surgery, tumour size, gender or time since radioiodine therapy with various physical and social aspects of functioning included in the UW-QOL questionnaire. Interestingly, there is an opinion that the quality of life mainly determines the quality of life after treatment (Taïeb *et al.*, 2009). The author of this thesis speculates that while the results of quantitative studies may show participants' average quality of life, some participants suffer more than others. Thus, support services must be available, and referral pathways must be established. Overall, studies showing minimal or no impact of the disease on people's lives are an insignificant minority. The vast majority of authors agree that thyroid cancer diagnosis and treatment have a negative impact on people's lives. The impact is amplified in people experiencing recurrence, persistent disease, and metastasis.

Interestingly, all qualitative studies agree that participants' cancer impacts their quality of life or significantly affects their life experiences (Sawka *et al.*, 2009; Easley, Miedema and Robinson, 2013; Misra *et al.*, 2013; Gallop *et al.*, 2015; Hedman, Strang, *et al.*, 2017; Randle *et al.*, 2017). However, some discrepancies between the qualitative studies showing adverse effects and quantitative studies showing little or no effect could be because there is a difference in data collection and how it affects responses. In addition, the deep conversation can reveal more reflections and feelings about patients' experiences, providing different perspectives on the situation. Thus, it is essential to appreciate input from qualitative enquiries.

The effects on quality of life can last, not only during treatment and soon after but also in the long-term (Banach *et al.*, 2013; Gamperet *et al.*, 2015; Grogan, Aschebrook-Kilfoy and Angelos, 2016) even 15 years after treatment (Hedman, Djärv, *et al.*, 2017). Even without recurrence, it can cause long-term worry about recurrence that can affect the quality of life (Hedman, Djärv, *et al.*, 2017). In some cases, the decrease in quality of life may be explained by the fact that about a fifth of all patients has a disease recurrence. Most recurrence happens in the first few years following the initial diagnosis. For some patients, however, it can take decades for the disease to recur (Grogan, Aschebrook-Kilfoy and Angelos, 2016; Lubitz *et al.*, 2017).

Therefore, lifelong follow-ups are necessary to monitor the condition and repeat the treatment if

needed (Lubitz *et al.*, 2017). Looking at the literature, it is clear that, at least for some people, the adverse effects on people last for many years after initial treatment, even when they are disease free.

Even though the majority of authors agree that quality of life is affected, it is essential to note that, for most people, quality of life improves with time (Ramim *et al.*, 2020) or goes back to near-normal or normal levels (Giusti *et al.*, 2011). For example, (Hoftijzer *et al.*, 2008) shows that after 12 years (SF-36) and 20 years (MFI-20), quality of life returned to normal. The authors justified it by suggesting that with time, treatment, follow-ups, and tests become less frequent; it does not take up much time in a participant's life. Unpleasant treatment-related issues become less critical and more comfortable to deal with. Thus, the quality-of-life results improve. The study was based on a sample of 153 survivors of differentiated thyroid cancer. In (Grogan, Aschebrook-Kilfoy and Angelos, 2016) study, the results improved by year five post-treatment. According to (Aschebrook-Kilfoy *et al.*, 2015). Quality of life plateaus after five years and then gradually improves. Gómez *et al.* (2010) found a high correlation between time and improving quality of life; the more time elapsed since the diagnosis, the better the improvements in quality of life. Interestingly, some patients in Huang *et al.*'s (2004) study reported lower quality of life after 18 months compared to within the first 18 months post-treatment. In general, however, authors think that initially, patients concentrate on treatment, but when it is finished, they experience more quality-of-life impairment. As a result, changes in quality of life should be continuously reported.

Surprisingly, some survivors of rare cancers stated that following their disease, they have experienced positive effects in their lives. For example, some felt lucky, and others decided to improve their lifestyle, for instance, by quitting smoking and drinking (Anh *et al.*, 2016). Similar results were reported (Gallop *et al.*, 2015). In this study, positive changes resulting from thyroid cancer included exercise, better lifestyle, change in life outlook, and changing jobs to spend more time with family. It could be attributed to the phenomenon known as post-traumatic growth. Post-traumatic growth is the phenomenon of increased personal strength after a significant life event, for example, being diagnosed with cancer (Misra *et al.*, 2013). It is interesting how sometimes adverse life challenges positively impact people.

However, while the quality of life generally improves, some symptoms post-treatment may linger for many years. Thyroid cancer survivors still suffer from various symptoms and functioning challenges five years after diagnosis (Crevenna *et al.*, 2003; Husson *et al.*, 2011). Examples of such symptoms are getting tired quickly and memory loss (Easley, Miedema and Robinson, 2013). Prolonged symptoms may be one of the reasons that, for some people with

thyroid cancer, adverse effects on lives last for many years after treatment.

### **2.3.3 Comparison with other cancers**

Patients' quality of life is frequently shown to be similar to the quality of life of patients with more aggressive forms of cancer like colon, glioma or gynaecological cancer, and the reason for this is currently unknown (Applewhite, James, *et al.*, 2016). Moreover, cancer type does not have a strong influence on Fear of Cancer Recurrence (FCR). Reported FCR severity is not different among survivors of rectal cancer, colon cancer, thyroid cancer, Hodgkin lymphoma, non-Hodgkin lymphoma, melanoma and endometrial cancer (van de Wal *et al.*, 2016). Comparable or worse quality of life compared with breast, colorectal and prostate cancer was reported by (McIntyre *et al.*, 2018a). Survival prognosis may have little correlation with QoL in cancer survivors (Aschebrook-Kilfoy *et al.*, 2015). Thus, it can be concluded that it is a fact of having cancer that negatively affects people, not cancer specifics like prognosis.

However, some authors speculate that inequalities in cancer support provision may be responsible for the high incidence of poor quality of life in thyroid cancer. Illustrative is that other cancer survivors have an abundance of additional services like CBT therapies, proper psychological support, education, and lifestyle interventions (Grogan, Aschebrook-Kilfoy and Angelos, 2016). In addition, there is a large amount of literature on the QOL of breast cancer survivors, and it is nationally a highly recognised disease. It, in turn, makes health care staff who care for breast cancer patients pay attention to QOL. Consequently, it can be argued that thyroid cancer survivors are not given the same broad support for their diagnosis and, as a result, do not have as good QOL.

### **2.3.4 Demographic factors impacting quality of life in people**

The literature regarding demographic factors and their effect on the quality of life is limited. For example, only one study looked at marital status. Li *et al.* (2019) concluded that being unmarried or divorced is an independent risk factor for decreased quality of life. However, the study looked at participants up to 3 months after thyroidectomy and had a small sample. Longitudinal studies with a bigger sample are needed to explore this correlation further. Furthermore, there are no studies regarding the differences in the quality of life of thyroid cancer patients from different ethnical backgrounds.

## Education

Lower levels of education are associated with a higher quality of life, as reported by women with higher levels of education (Husson *et al.*, 2011; Aschebrook-Kilfoy *et al.*, 2015; Goldfarb and Casillas, 2016a; Rogers *et al.*, 2017). A possible reason for this correlation is that education has other socio-economic repercussions, such as better financial situation and better access to information. However, other demographic factors were not correlated with decreased quality of life, for example, country of birth or marital status (Hoftijzer *et al.*, 2008).

## Age

Age seems to be one of the factors affecting the quality of life that can be established when looking at the literature. However, the results vary. Younger age at the diagnosis is correlated with decreased quality of life, especially for young females (Aschebrook-Kilfoy *et al.*, 2015; Goldfarb and Casillas, 2016; Rogers *et al.*, 2017). Levels of reported nausea and vomiting improve with age; Young adults, when compared with older patients, reported higher levels of general emotional issues and anxiety, as well as headaches, chilliness, self-consciousness about their scar, low interest in sex (Aschebrook-Kilfoy *et al.*, 2015; Rogers *et al.*, 2017), and higher levels of pain (Vega-Vázquez *et al.*, 2015). However, they reported fewer complaints related to voice, neuromuscular, sympathetic, or mouth/throat symptoms (Goldfarb and Casillas, 2016a).

Other authors concluded that quality of life decreased with older age. Older people have a lower quality of life (Taïeb *et al.*, 2009; Giusti *et al.*, 2011), especially those with advanced diseases (Giusti *et al.*, 2011). Levels of physical and emotional functioning decrease with the age of thyroid cancer patients (Rogers *et al.*, 2017). This, the author speculates, could be because older patients have an additional burden of comorbidities. Another reason for decreased quality of life in older patients may be that older people experience more pain (Singer *et al.*, 2016). Older patients (over 50 years old) scored worse on physical functioning (Husson *et al.*, 2011). Moreover, postmenopausal women had a significantly lower quality of life than pre-menopausal women (Hedman, Djärv, *et al.*, 2017). Increasing age positively affects emotional functioning; however, it negatively influences physical and cognitive functioning (Lee *et al.*, 2010). The discrepancies between the results may be because studies may have different profiles of participants. It is most likely the case that some older people suffer more than average. Similarly, some young people may suffer more than average due to various determinants.

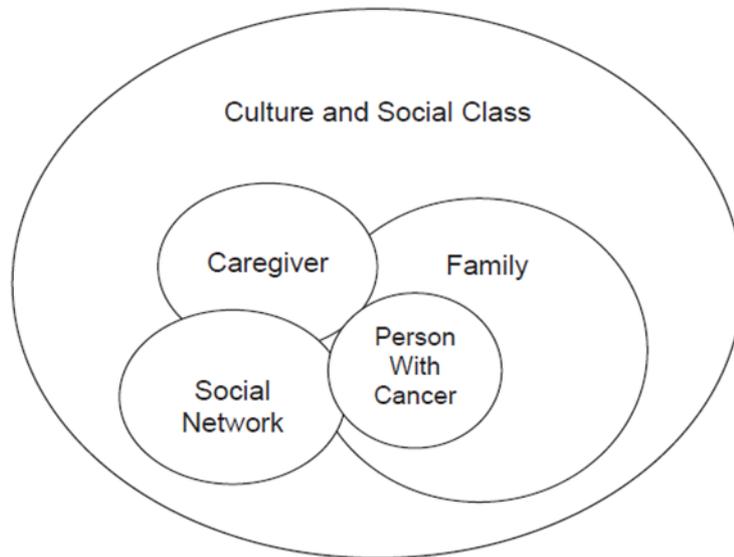
## **Gender**

There are differences in how men and women go through critical life events and how this affects them. Women have a significantly lower quality of life in general as well as looking at the different subgroups scores when compared with males (Lee *et al.*, 2010; Giusti *et al.*, 2011; Aschebrook-Kilfoy *et al.*, 2015; Grogan, Aschebrook-Kilfoy and Angelos, 2016; Carlson *et al.*, 2019), especially in the physical domain (Lee *et al.*, 2010; Bãrbuş *et al.*, 2017). (Gamper *et al.*, 2015), looked into the influence of sex and age on HRQOL. Female patients had many more problems than male patients, while the difference between men and women was only marginal in the general population. Female patients experience more distress (Carlson *et al.*, 2019), insomnia, feeling chilly, and loss of libido (Rogers *et al.*, 2017), which all can impact their lives. Interestingly, men scored higher in fear of cancer returning (Rogers *et al.*, 2017).

### **2.3.5 Culture, religion and spirituality**

Another group of factors that are significant in the way people react to adverse life events are cultural factors such as social culture (Helliwell and Huang, 2008). ‘Cancer is more than a biological disease. Cultural factors are involved at every stage in the cancer journey, from prevention to palliative care (Dein, 2006, p. 2). Culture can be described as a set of norms, values, beliefs, objects and behaviours of a particular group. The cancer experience can not be considered in isolation from the context of culture. There are many different aspects of culture that can impact cancer experience. For example, factors like poverty, social class, ethnic minorities, cultural values and beliefs, religion, self-conceptualisation of health and other social determinants of care (Dein, 2006).

**Fig. 2.2 Model placing person facing cancer within the culture and social class** (Marshall *et al.*, 2011).



### *Values*

The cultural background provides social values and goals (Adler and Seligman, 2016). For example, one study looked at differences in the Meaning of life in advanced cancer between cancer patients from Spain, Switzerland and Germany. Spanish cancer patients rely more on relationships with other people in constructing their meaning of life (MiL) (Tomás-Sábado *et al.*, 2015). German and Swiss place more importance on nature and animals than Spanish (Tomás-Sábado *et al.*, 2015). It shows how people from different cultures value different things. It can affect the way they cope with the disease. It could also affect what kind of interventions would be suitable. There are also differences in how people from different cultural backgrounds perceive cancer pain. It also impacts health-seeking behaviours (Kwok and Bhuvanakrishna, 2014).

### *Beliefs*

Cancer can also be associated with beliefs, taboos and myths. One of the myths, for example, is the belief that cancer is a fatal disease, that it can be contagious, or that it happened as a punishment (Daher, 2012). Furthermore, various health-related and cancer-related beliefs exist among different people and cultures. For example, the belief that cancer is an effect of “bad karma” or “bad feng shui” can be shared in some Asian minorities living in the UK (Licquish *et al.*, 2017)

### *Attitudes*

There are cultural differences in attitudes towards cancer. Attitudes include pessimism, fear, secrecy, stigma, stoicism, and pragmatism (Licqurish *et al.*, 2017). In their study, all minorities (African, Arabic, Latino, Hispanic, Chinese, South Asian and African American) from the USA and the UK believed that cancer diagnosis is the death sentence. Fear can also motivate or inhibit help-seeking when experiencing worrisome symptoms. Also, stigma was reported. Although stigma is usually associated with mental health disorders (Nakash, Nagar and Levav, 2015), there are reports of stigma in patients with cancers, for example, lung cancer (Chambers *et al.*, 2015) and breast (Else-Quest *et al.*, 2009). Stigma can affect QoL in cancer patients (Kim, 2019). Moreover, fears and symptoms can cultivate the stigma of having cancer (Daher, 2012). The stigma can be more evident among some ethnic minorities living in the UK (Licqurish *et al.*, 2017).

### *Challenges and barriers*

In a multicultural society, some challenges in a healthcare setting include language barriers, embarrassment, and discrimination (Licqurish *et al.*, 2016). For example, cancer patients not advanced in the local language may struggle to understand the information provided by medical staff. Using interpreters can also be challenging as there is evidence that even professional interpreters may misinterpret or simplify information (Butow *et al.*, 2013). Social class has a significant impact on cancer health provision and person and their family. Social class impact on a cancer patient is often underestimated. For example, people from lower socio-economic backgrounds may have access to health services in the later stages of cancer, where their chances of cure are decreased (Licqurish *et al.*, 2016). It should be considered in all aspects of cancer care (Marshall *et al.*, 2011). The model placing patients with cancer within their social environment that includes class and culture can be seen in Fig. 2.2 above.

### *Provision of culturally sensitive care*

Society's culture is developing and changing, and services should also change (Thomas and Leon, 2021). Services should meet the needs of developing society (Greene-Moton and Minkler, 2020). Health care professionals should have cultural competence, understanding that we cannot fully understand another person and their cultural needs (Greene-Moton and Minkler, 2020). Still, knowledge and understanding of other cultures and cultural impacts are essential for health care staff (Broom *et al.*, 2019). It is also part of mandatory training in the NHS.

However, it is also important to avoid stereotyping people, which takes away their individualism (Dein, 2006).

### *Religion*

Similarly, the religious needs of people with cancer are equally important. Religion is ‘a system of faith and worships expressive of an underlying spirituality which is frequently interpreted in terms of particular rules, regulations and practices, as well as belief in the content of the named religion’ (Koffman *et al.*, 2008, p. 781). Interestingly, people with cancer are more likely to have religious beliefs when compared to general populations (Ross *et al.*, 2008). Kraus, (2022) concluded that faith stays constant for some participants and grows for others, but it is unlikely to decrease or diminish.

Religious beliefs are essential for some patients coping with cancer (Dakhli *et al.*, 2013; Kraus, 2022). It can also help to come to terms with having a disease (Crane, 2009). It is one of many patients' most critical factors in coping with cancer (Salsman *et al.*, 2015; Ahmadi *et al.*, 2019; Merath *et al.*, 2020). However, some authors say there is limited evidence on the relationship between psychological wellbeing and spirituality (Schreiber and Brockopp, 2012). Others found a connection between religion and spirituality and the mental health of cancer patients (Salsman *et al.*, 2015). Psychological wellbeing may be connected to belief systems before diagnosis and questioning one's belief system may lower wellbeing (Schreiber and Brockopp, 2012).

Although religion and spirituality can assist women with adjusting to their new cancer situation, they can also benefit from side effects (Toledo, Ochoa and Farias, 2021). The authors recommend the development of meaning-centred interventions that incorporate spirituality to support women. Zarzycka *et al.* (2019) used the Religious Comfort and Strain Scale to establish the role of religion in women with cancer. They concluded that religion gives hope. Hence it can protect from anxiety.

Evidence suggests that religion can have a positive impact on health. For example, in one study, Catholic beliefs contributed to positive health behaviours and attitudes (Leyva *et al.*, 2014). Also, religion can even prevent the development of disease in the first place. For example, some religious beliefs may stop people from risky behaviours that may be seen as restraining smoking, overeating, and sex can protect people from many forms of cancer (Koffman *et al.*, 2008; Crane, 2009). However, there are differences in religion. For example, one study looked at differences in the meaning of religion between the Black Caribbean and White British patients with advanced cancer. The results suggest that the Black Caribbean have stronger

beliefs, and they play a more crucial role in their experiencing of cancer. However, both ethnic groups reported benefits derived from their faith (Koffman *et al.*, 2008).

## **2.4 Experience of thyroid cancer, including Treatment and Hospital Care and its impact on lived experience and quality of life.**

### **2.4.1 Thyroid surgery**

Post-operative quality of life declines immediately after the operation, only to improve early (Husson *et al.*, 2011; Lubitz *et al.*, 2017), even as soon as six months after the treatment (Lubitz *et al.*, 2017). There are no significant differences in quality-of-life scores in the follow-up (1 year) and pre-treatment (Husson *et al.*, 2011; Lubitz *et al.*, 2017). However, persistent disease and early recurrence significantly impact the quality of life in both pre-op and post-op points. Other factors affecting the quality of life are the quality of surgery (Dimov, 2013; Bãrbuș *et al.*, 2017).

Type of surgery can impact the quality-of-life results (Husson *et al.*, 2011). Lobectomy means that thyroid hormone replacement therapy may not be needed. Thus the quality of life can be better (Cox *et al.*, 2018). However, symptoms of hypothyroidism can still be present in some patients (Cox *et al.*, 2018). According to Bongers *et al.* (2020), there is no significant difference in HRQoL between total thyroidectomy and hemithyroidectomy. However, the fear of recurrence was higher in the hemithyroidectomy group (Bongers *et al.*, 2020). Li *et al.* (2019) concluded that lobectomy was correlated with lower quality of life among his respondents.

One study compared the quality of life between patients with traditional thyroidectomy (123 patients) and patients with single-ported accessed transaxial endoscopic thyroidectomy (Ma *et al.*, 2016). Operation time was increased in endoscopic surgery. There were no significant differences between the groups in speech, taste, and psychological functioning. Interestingly, the mean physical composite and appearance scores were significantly higher in the experimental group compared to the control group at one month and six months following the surgery. However, patients in the experimental group scored higher (better) in areas like appearance, satisfaction with role-physical, appearance, general health and bodily pain. The authors concluded that this could be an optional technique as it is safe and benefits patients (Ma *et al.*, 2016).

There are no differences in quality of life between papillary and follicular thyroid cancers (Wiener *et al.*, 2019). Regarding neck dissection, quality of life is affected in two ways, positive

when the quality of surgery is very high and adverse when the surgery is of poor quality and results in complications (Dimov, 2013). A more recent study (Nickel *et al.*, 2019) concluded that patients with total thyroidectomy were 1.5 times more likely to have decreased quality of life than hemithyroidectomy. This score increased to 2.3 times if patients also had neck dissection. To summarise, quality and symptoms related to surgery affect the lives of patients with thyroid cancer and this element is still understudied.

### **Impact of scars**

Scarring from surgery can impact patients' activities, appearance and social relationships, and quality of life (Huang *et al.*, 2004). Body image issues are possible because of scarring (Easley, Miedema and Robinson, 2013). It has been noticed that the QoL in patients with visible scars is poorer than in those with invisible lesions (Bock *et al.*, 2006). Moreover, patients can experience pain and tightness when turning their heads and speaking loudly (Huang *et al.*, 2004). However, the impact of scars on social relationships and appearance was not associated with the QoL score. In one study, the authors (Choi *et al.*, 2014) looked at the quality of life-related to post-surgical scar in thyroid cancer patients. Traditional thyroidectomy, as opposed to the single-entry method (single-ported accessed transaxial endoscopic thyroidectomy), is still preferred as it allows good direct exposure of the area for accurate gland dissection. It is also safer. Quality of life scores was not associated with characteristic features of thyroid scars (for example, type and duration) or with patient characteristics (sex, age, BMI, employment status, marital status, smoking and education). Thus, the presence of the scar itself and not its characteristic or patient demographics is problematic.

### **2.4.2 Radioactive iodine treatment (RAI)**

Another phase of thyroid cancer treatment that can cause impairment in quality of life is radioactive iodine treatment. Patients that underwent RAI show a significantly lower quality of life between the post-operative period and follow-up (Almeida, Vartanian and Kowalski, 2009; Lubitz *et al.*, 2017). Overall, emotional (Husson *et al.*, 2011; Anh *et al.*, 2016) and physical aspects of quality of life were affected. Most respondents saw their RAI treatment as a negative experience in this study (Anh *et al.*, 2016). RAI and dose were significant factors affecting the quality of life in studies by (Almeida, Vartanian and Kowalski, 2009; Haraj *et al.*, 2019).

However, over 30 months post-RAI, patients' scores on the role and emotional functioning, fatigue, pain and dyspnea, and pain (major improvement) improved (Gamper *et al.*, 2015). Even studies looking at the quality of life up to 3 months after the RAI reported improvement

(Ramim *et al.*, 2020). In contrast, other results showed no significant difference between surgery only and surgery plus RAI (Lee *et al.*, 2010). In addition, another author (Lee *et al.*, 2010; Vega-Vázquez *et al.*, 2015) found that increased and cumulative doses of radioactive iodine did not further impact the quality of life. Surprisingly, although this treatment is a source of worry and is surrounded by many misconceptions (Bârbuş *et al.*, 2017), it does not present long-term quality of life changes. Another author (Husson *et al.*, 2013) agrees that the stress of the treatment is highly correlated with decreased quality of life. 71% of participants in the study were affected by stress related to the procedure.

### **Impact of isolation (during RAI)**

Isolation is a part of thyroid cancer treatment that requires participants to stay isolated in a private hospital room for about 2-5 days. This unusual situation can be a source of distress for people (Sawka *et al.*, 2009; Easley, Miedema and Robinson, 2013; Anh *et al.*, 2016). Isolation during RAI treatment psychologically affected participants as they were isolated from family, friends and the healthcare team (Easley, Miedema and Robinson, 2013; Anh *et al.*, 2016). One participant in this study expressed having felt like a zoo animal or like having the plague. The fact is that this is when people need more support and due to the treatment practicalities and risks, this is when they have to be physically isolated from other people. Some participants (regardless of gender) stated that they felt isolated and distressed during the 3-day hospital stay. For some patients, staying isolated in the hospital for a few days can be a distressing experience.

### **2.4.3 Impact of hormone replacement therapy**

Following surgery, patients require lifelong hormone replacement therapy, which can impact their quality of life (Ying *et al.*, 2009; Banach *et al.*, 2013; Easley, Miedema and Robinson, 2013). However, when the dosage was correct, participants reported a low impact on HRQoL (Gallop *et al.*, 2015). Aschebrook-Kilfoy *et al.* (2015) concluded that adjusting to the right dose can be difficult, and some patients struggle with lifelong adjustment needs (Husson *et al.*, 2013). The challenges with thyroid replacement therapy include difficulty finding the correct dosage, dealing with an imbalance of hormones, and dealing with the side effects of medications. Therefore, lifelong therapy may impact HRQOL more than previously anticipated (Kansagra, McCudden and Willis, 2010; de Oliveira Chachamovitz *et al.*, 2013; Edafe *et al.*, 2014; Gamperet *et al.*, 2015).

Interestingly, researchers (Hoftijzer *et al.*, 2008) measured serum TSH levels during the assessments and in follow-ups, which showed that TSH values over time are not a significant

independent predictor of quality of life. It was also reported by a recent study by (Laura *et al.*, 2019) when the authors concluded that the experience of cancer and not alterations in thyroid hormone function affect the quality of life. Thus, it can be argued that symptoms may be a better indicator of hormonal imbalance than TSH measurements. The evidence is conflicting; thus, it can be concluded that the necessity for hormone replacement therapy affects the quality of life in situations of hormonal distortion, but when the dosage is optimal, the symptoms should decrease, improving the quality of life.

#### **2.4.4 Involvement in decision making**

Being involved in decision-making is an essential part of the cancer journey. Patient-centred decision-making should be part of optimal cancer care (Herrmann *et al.*, 2019). Patients should be well informed and able to make positive decisions with their doctor (Bae, 2017).

Unfortunately, not being involved in the decision-making process is reported in the literature (Elit *et al.*, 2003; Kreling *et al.*, 2006; Herrmann *et al.*, 2019). People may be too overwhelmed with treatment options, inhibiting their ability to make a decision (Herrmann *et al.*, 2019).

When looking at thyroid cancer studies specifically, the results are varied. Involvement in decision-making about treatment is significant for some patients (Sawka *et al.*, 2009). Most participants in their study stated they did not feel included in the decision-making process regarding RAI treatment. The wish for involvement in RAI decision-making was variable. Some participants preferred the doctor to make the decision, and others felt they did not have a choice. Some had felt empowered and involved. Only two participants felt that the decision was solely their own. Participants stressed the importance of being provided with all the benefits and negatives of the treatment in order to be able to make a decision. In their later study Sawka *et al.* (2012) carried out a secondary study with 44 participants in which the RAI decision had been finalized. The objective was to measure the relationship between decision regret, patient involvement, and treatment results. The results of this study showed that overall regret regarding the decision to have RAI was low. However, shared decisions resulted in lower levels of regret than doctors-only decisions. Decision regret was similar in people who decided to undergo RAI and those who decided not to. The authors concluded that involvement in decision-making is significant and results in lower levels of regret compared to lack of involvement in decision-making regarding RAI treatment. For some people, being included in the decision-making process is more important than others. However, patients should always be aware that they can have more input into decisions if they wish.

#### 2.4.5 Information provision

Information provision is repeatedly reported as one of the significant factors impacting the lives of people with thyroid cancer (Wiener *et al.*, 2019). As a result, the understanding of the demand for information on thyroid cancer is increasing. Doctors must be very well informed about the disease's symptoms and other aspects (Duan *et al.*, 2015). Participants were generally satisfied with the information provided, including information about prognosis, tests, medication, treatment, isolation and surgery (Roberts, Lepore and Urken, 2008). On average, participants felt that their HCP were well informed and provided information and answered questions (Roberts, Lepore and Urken, 2008). Interestingly, younger females report more unmet information needs than older males (Hyun *et al.*, 2016).

However, it has been noted that some doctors overestimate their information provision, while patients feel not adequately informed in some areas, for example, about the possible complications of surgery. Furthermore, 29% of patients thought that the risks associated with RAI treatment were not sufficiently discussed (James *et al.*, 2018). In another study, less than 50% of respondents received information about their treatment's long-term health effects and emotional concerns (Morley and Goldfarb, 2015). Inadequate information about where to access emotional and psychological support, how to deal with fears about side effects, getting support for family members, dealing with emotions after diagnosis and causes of cancer (Roberts 2008), potential risks and benefits of RAI, side effects, newer treatment, other malignancies, risks for families, financial assistance (Sawka *et al.*, 2016) were reported. More unmet information needs include aftercare, practical issues, psychosocial concerns (Morley and Goldfarb, 2015; Hyun *et al.*, 2016) and psychological issues (Hyun *et al.*, 2016), adverse side effects of body scans, how to deal with side effects, alternative treatments, where to get the most up-to-date and current information regarding thyroid cancer (Roberts, Lepore and Urken, 2008). There are areas of the thyroid cancer journey that should be addressed when providing patient information.

Better information provision improves levels of distress and perception of the disease (Wiener *et al.*, 2019). Moreover, informed patients can cope better than uninformed patients (Duan *et al.*, 2015). Providing sufficient information is an excellent way to decrease distress in cancer patients, and interventions should be developed to help manage distress. Lack of sufficient information is one of the illness's most challenging aspects (Banach *et al.*, 2013). According to (Husson *et al.*, 2013), a good level of disease-specific information (targeted to thyroid cancer patients) improves disease perception. This result was confirmed by (Wiener *et al.*, 2019). Furthermore, quality information provision impacts fear of recurrence. People who were satisfied with the information they received reported lower levels of fear, and people who would

have liked to receive more information scored higher on fear of recurrence (van de Wal *et al.*, 2016). As seen above, being informed about all aspects of the disease, treatment and long-term implications is very important for patients.

The primary information source for patients is health care professionals, mainly doctors (Roberts, Lepore and Urken, 2008; van de Wal *et al.*, 2016). The Internet was rated less important (van de Wal *et al.*, 2016). Most respondents in (Roberts, Lepore and Urken, 2008) study (62.9%) used the Internet, 41.9% used informational leaflets, 25.8% used books, and 1.6% used videos. If available, 92.9% would use the Internet, 83.6% would use leaflets, 71.7% would use books, and 55.4% would use a video. 73.8% of respondents never used self-help books, but 69.3% would if they were available. 68.8% of participants would use an organiser, and 37.2% would use journaling if made available. Most respondents did not attend an organised educational group (91.95%), but 43.6% indicated that they would if it was available. (Kuenzel *et al.*, 2018) assessed the quality of German online information for thyroid cancer patients. The results were mixed. Official health-related sites provided good quality information, and information on other non-health-related websites was of poor quality. The authors concluded that the most available info for patients was low quality. The quality of online information in the UK has not been assessed.

#### **2.4.5.1 Support and information needs of people with thyroid cancer**

Studies looking at the support needs of people with thyroid cancer agree that this group of oncological patients have much unmet information and support needs (Roberts, Lepore and Urken, 2008; Banach *et al.*, 2013; Easley, Miedema and Robinson, 2013), and significantly younger patients (Easley, Miedema and Robinson, 2013). It was also concluded in a systematic review (Hyun *et al.*, 2016) looking at the unmet information and psychosocial support needs of patients with thyroid cancer. The review included only seven studies as the area is still under-researched. (Morley and Goldfarb, 2015) concluded that the majority of support needs are unmet, they recommend more qualitative research to identify unmet needs and design interventions. Other authors concluded that gaps in support provision are substantial (Banach *et al.*, 2013). Support options include self-help, health, social, and professional psychological interventions (Easley, Miedema and Robinson, 2013).

Lack of adequate support is a frequent complaint among patients (Easley, Miedema and Robinson, 2013). Some patients reported not receiving sufficient information about support, especially psychological support (Roberts, Lepore and Urken, 2008). Some areas of insufficient support were identified, including access to alternative treatments, reasons for developing

cancer, dealing with family, and fear of cancer returning. Also, one of the most significant areas was the lack of information about access to emotional support. In this study, 14.5% accessed support from a dietitian, 11.8% counselling psychologist, 4.8% psychiatrist, 4.8% social worker and 4.8% from religious or spiritual support. The percentage of people using the services if offered is much higher (Roberts, Lepore and Urken, 2008). The authors speculated that clinicians may not always enquire about patients' emotional states and may not always disclose their issues to a doctor. According to Banach *et al.* (2013), 92.6 % had not offered any psychological support at diagnosis, and 63% received no written thyroid cancer-specific information. Sometimes, patients decide not to access available support mainly because they feel they do not need support (Easley, Miedema and Robinson, 2013). However, some participants are not accessing the support needed due to feeling unworthy of support programmes (Easley, Miedema and Robinson, 2013).

## **2.5 Physical health, side effect and thyroid cancer**

### **2.5.1 The health/disease perception**

Disease/health perception is an essential aspect of the cancer journey. There is evidence in oncology literature that there is a correlation between worse emotional functioning and threatening illness perceptions (Rozema, Völlink and Lechner, 2009; Traeger *et al.*, 2009; Wiener *et al.*, 2019). Disease perception is a significant determinant of quality of life (Hirsch *et al.*, 2009). Thyroid cancer patients perceive their disease on an emotional and subjective level that is not related to the severity of their prognosis (Hirsch *et al.*, 2009). Perception of the disease tends to worsen in adults and older adults (Husson *et al.*, 2020) and females (Giusti *et al.*, 2020). People see thyroid cancer as a significant and severe disease (Randle *et al.*, 2017). Thyroid cancer patients with a negative perception of their disease report lower quality of life (Schoormans *et al.*, 2020). In one study, patients with thyroid cancer feel that their health is good, but it could be better. Only 4% of participants (out of 75) said they feel wrong about their health (Gómez *et al.*, 2010). People perceive their disease as severe, which differs from some health care providers. However, in thyroid cancer, patients' perception of their thyroid cancer is still understudied (Wiener *et al.*, 2019).

### **2.5.2 The general health and comorbidities of people with thyroid cancer**

General health and presence of comorbidities of cancer patients. Pre-existing comorbidities may have a detrimental effect on cancer treatment and quality of life (Sarfati, Koczwara and Jackson, 2016). For example, American data show that 40% of people with cancer have at least one

chronic condition, and 15% have more than two co-existing conditions (Edwards *et al.*, 2014). It affects their quality of life, overall survivor, and probability of being cured of their cancer (Cho *et al.*, 2013). In addition, cancer research shows that many people suffer from other health problems at the point of diagnosis. It can provide further challenges.

Looking at the health of thyroid cancer specifically, patients from Vega-Vázquez *et al.* (2015) study reported that 82.7% of participants stated that their overall health is the same or better now than before their treatment. This study's overall conclusion suggests that the general impact of thyroid cancer on overall health is minimal. However, some people diagnosed with thyroid cancer have different co-existing health problems. People with comorbidities have worse results in all domains of quality of life. Results suggest that the more comorbidities people have, the poorer quality of life they experience (Hedman, Djärv, *et al.*, 2017). Comorbidity is also associated with higher fear of recurrence (van de Wal *et al.*, 2016). In this study, participants with comorbidities reported significantly and clinically worse physical role functioning compared to the general population of Sweden (Hedman, Djärv, *et al.*, 2017).

Interestingly, scores in quality QoL among thyroid cancer patients after their operation are similar to those among people with chronic conditions. It means that thyroid cancer affects the quality of life, similarly to chronic long-term health conditions (Huang *et al.*, 2004). Although the thyroid cancer population is not free of other conditions, it provides a further area for consideration when dealing with TC patients. This consideration should be part of optimal, holistic, and person-centred care.

### **2.5.3 Physical Side effects of thyroid cancer treatment**

It seems that the physical aspect of the quality of life of people with thyroid cancer is relatively high (Roberts, Lepore and Urken, 2008). Most thyroid cancer patients report various physical problems (Buchmann *et al.*, 2015; Hedman, Djärv, *et al.*, 2017). For example, one study reported that 88% reported having symptoms, 42% reported significant physical symptoms, and 46% had moderate physical symptoms. Thus, 18% of people had no physical symptoms (Hedman, Djärv, *et al.*, 2017). In Gómez *et al.* (2010) study, 45% of participants in this study had no significant symptoms related to thyroid cancer treatment. However, when present, physical side effect lives in patients. Statistically and clinically speaking, patients that reported major symptoms had significantly lowered QoL, measured by SF-36, compared with people without significant physical symptoms (Hedman, Djärv, *et al.*, 2017). There are some differences between self-reported and diagnosed rates of some side effects. The prevalence of voice changes is 54.9% in this study population. However, the literature suggests this should be

no more than 5%. The surgical incision, hypocalcemia, weight gain and side effects from medications were reported at a rate 10-fold higher than expected (Aschebrook-Kilfoy *et al.*, 2015). Some people with thyroid cancer do not suffer from any physical complaints resulting from their disease. However, if present, they have a detrimental effect on people's lives.

## **Fatigue**

Fatigue is one of the most common physical side effects reported by patients with thyroid cancer (Huang *et al.*, 2004; Roberts, Lepore and Urken, 2008; Gómez *et al.*, 2010; Lee *et al.*, 2010; Roerink *et al.*, 2013; Duan *et al.*, 2015; Gallop *et al.*, 2015; McIntyre *et al.*, 2015; Anh *et al.*, 2016; Alhashemi *et al.*, 2017; Rogers *et al.*, 2017). Fatigue can affect mental health and wellbeing (Huang *et al.*, 2004; Rogers *et al.*, 2017). In Alhashemi *et al.* (2017), 52.5% of participants reported feeling unusually fatigued in the past week, mild - 58.6% (120 out of 203), moderate - 30.9% (63/203) and severe - 10.3% (21/203), respectively. Only 7.4% (15/203) had a fatigue score of 0/10. In Huang *et al.* (2004) study, many participants reported fatigue (61%) after the operation, and more than one-third still had fatigue (41%) in the month prior to the interview. In addition, 76% of participants stated they experienced sudden fatigue attacks (Husson *et al.*, 2013). Most of the participants in Gallop *et al.* (2015) study reported that their daily activities are affected due to feeling tired, having a lack of energy and brain fog. Others complained about other symptoms like total apathy or restlessness (Duan *et al.*, 2015), sudden attacks of tiredness, and physical exhaustion (Singer *et al.*, 2016). These symptoms are correlated with low quality of life (Singer *et al.*, 2016). Fatigue is a common issue for thyroid cancer patients and is detrimental to their quality of life.

In literature, very little information can be found about factors affecting fatigue in thyroid cancer. Fatigue was significantly worse in women, unemployed (employed individuals, homemakers/caregivers, students, retirees or unable to work due to disability) compared to others, as well as for people with recurrent disease and those with RAI treatment (Alhashemi *et al.*, 2017). The authors found that increased physical activity was significantly associated with reducing fatigue. Other factors like age, gender, T4 levels, and years since surgery were not significantly associated with fatigue levels. The authors speculated whether TC survivors with fatigue are at increased risk of loss of income or may be affected by other comorbidities resulting in unemployment and fatigue. Alternatively, that unemployment may impact fatigue. Fatigue is more common in women and unemployed as well as people with persistent and recurrent diseases.

Another exciting aspect of thyroid cancer treatment is whether patients experience pain. Face-to-

face interviews were carried out with 75 participants with thyroid cancer. The most significant factor in pain scores was age on the diagnosis. Younger patients (<45-year-old) experience significantly more pain (Vega-Vázquez *et al.*, 2015). Moreover, patients with higher doses of iodine also scored more in the pain domain (Valachis and Nearchou, 2013; Vega-Vázquez *et al.*, 2015). Joint and muscle pain are among the most commonly reported side symptoms (Rogers *et al.*, 2017). The study by (Gkatzia *et al.*, 2021) explored the HQoL in a cross-sectional study and concluded that a year after the treatment, bodily pain was still present while other aspects of quality of life improved. Overall, pain is not a very significant side effect, but it can be present, especially in younger patients.

### **Side effects related to surgery**

One side effect of surgery is voice changes related to nerve dysfunction responsible for voice (Schultz, Stava and Vassilopoulou-Sellin, 2003; Pelttari *et al.*, 2009; Gallop *et al.*, 2015; Rogers *et al.*, 2017). The voice changes include, for example, hoarseness (Easley, Miedema and Robinson, 2013; Hedman, Djärv, *et al.*, 2017) and even paralysis (Easley, Miedema and Robinson, 2013; Lubitz *et al.*, 2017). Huang *et al.* (2004) reported that around one-third of patients had symptoms like tetany (muscular spasms), hoarseness and tingling around the mouth following their thyroidectomy, lasting up to 6 months, while 10% of patients reported permanent symptoms. Interestingly, minor voice changes, tetany and tingling around the mouth were not that important for most people (Huang *et al.*, 2004; Hedman, Djärv, *et al.*, 2017). Conversely, according to (Singer *et al.*, 2016), voice changes are highly associated with decreased quality of life. A recent study confirms that voice abnormalities following surgery can be very prevalent (Kovatch *et al.*, 2019).

The following joint group of symptoms after thyroidectomy that affects people and their experience are those related to scars (Huang *et al.*, 2004; Easley, Miedema and Robinson, 2013; Choi *et al.*, 2014; Gallop *et al.*, 2015). In one study, these side effects and symptoms were reported in 64 patients (66.0%), including pruritus (dry skin) (38.1%), tightening (29.9%), pain (12.4%), and burning sensation (3.1%) (Choi *et al.*, 2014). The mean quality of life score was 9.02 (variation by 5.79) out of 12 possible with daily activities as an area greatly affected. Higher impairment of quality of life was associated with pruritus (itchy skin), pain, burning, or tightening. Therefore, a scar is unavoidable in traditional thyroidectomy. Moreover, 66.0% of patients experienced more than just one of the symptoms. Thus, it is essential to have scar-related post-surgical support in order to assist with symptoms (Choi *et al.*, 2014).

Mobility of people is affected after thyroidectomy. This, in turn, can affect the quality of life. The problems related to mobility are impairment (Gallop *et al.*, 2015), lack of physical contact

(46.9%) (Roerink *et al.*, 2013), muscle strength (40.0%) (Roerink *et al.*, 2013), Swelling (Gallop *et al.*, 2015), feeling tired, feeling slowed down and weak, issues with long walks and strenuous activities (Rogers *et al.*, 2017). In addition, neck discomfort is associated with decreased quality of life (Singer *et al.*, 2016).

Other side effects that can happen after the surgery are dysphagia (Schultz, Stava and Vassilopoulou-Sellin, 2003; Aschebrook-Kilfoy *et al.*, 2015; Gallop *et al.*, 2015; Singer *et al.*, 2016; Rogers *et al.*, 2017), numbness in the operation area, (Hedman, Djärv, *et al.*, 2017), scarring, dysfunction after neck dissection (Rogers *et al.*, 2017), paresthesia (burning and prickling sensation) (31.7%) (Roerink *et al.*, 2013), xerostomia (Rogers *et al.*, 2017) hypoparathyroidism (Dimov, 2013; Anh *et al.*, 2016). Moreover, parathyroid problems are possible following the surgery because they may be removed during surgery (Dimov, 2013). Symptoms of hypoparathyroidism were reported in 17 patients (3.3%) (Schultz, Stava and Vassilopoulou-Sellin, 2003). However, hypoparathyroidism has been reported to be correlated with decreased quality of life (Hoftijzer *et al.*, 2008). This conclusion was challenged by (Büttner *et al.*, 2020), whose study concluded that hypothyroidism as a result of thyroid cancer treatment significantly decreases HRQoL. Therefore, the authors suggest that these patients' quality of life is more affected than thyroid cancer patients without hypothyroidism. Determinants related to surgery but not associated with decreased quality of life are tumour classification, type of operations, tumour staging (Huang *et al.*, 2004), initial tumour node stage of metastasis, the total activity of I-131, tumour recurrence (Hoftijzer *et al.*, 2008).

More severe side effects or complications after surgery include recurrent laryngeal nerves palsy, thoracic duct injury, transection of cervical rootlets, spinal accessory nerve damage, seroma, and wound infection (Dimov, 2013). In addition, permanent vocal cord paresis was reported in 15.7% of cases, and in 5.9% of cases, tracheotomy had to be maintained (Wierzbicka *et al.*, 2014). Although thyroidectomy is a safe procedure, any surgery carries risks and side effects, some of which can even be permanent.

### **Side effects related to RAI**

Salivary morbidity is a problem related to salivary glands following radioactive iodine treatment (Rogers *et al.*, 2017). Most participants had side effects had short-lived side effects. In their study, nine participants (out of 15) reported at least one side effect in correlation to RAI, for example, salivary gland swelling, nausea, sore throat, changes in taste, rash, menstrual changes or hair thinning. Schultz, Stava and Vassilopoulou-Sellin (2003) reported impairment of salivary function in 17 patients (3.3%), taste disturbance (Gallop *et al.*, 2015), sialadenitis (infection of salivary glands) (Gallop *et al.*, 2015; Hedman, Djärv, *et al.*, 2017). The following

study showed rare symptoms related to RAI; only 4% of the patients reported salivary gland problems and xerostomia (Hedman, Djärv, *et al.*, 2017). In this study, low levels of problems with salivary glands (4%) can be explained by the low recurrence rate and thus low cumulative dose of radioactive iodine. RAI can have various temporary side effects affecting people shortly after the treatment.

Other side effects are long-lived or chronic side effects such as changes in taste, dry eyes, gum and dental problems. Salivary problems, if they occur, are troublesome (Sawka *et al.*, 2009). The effect of higher cumulative radioiodine doses associated with lower scores on the domains of chewing, swallowing, taste, speech or anxiety was not observed (Almeida, Vartanian and Kowalski, 2009; Sawka *et al.*, 2009). RAI-refractory recurrent, metastatic disease represents (Aashiq *et al.*, 2019) patients who took part in clinical trials reported additional side effects including anaemia and leukopenia, losing teeth (because of blocked salivary ducts), dry mouth where they had to sip water very often and carry a bottle with them everywhere (Gallop *et al.*, 2015). Salivary problems can be short on long-term side effects affecting everyday life.

Pregnancy outcomes and future fertility concern people with thyroid cancer, especially among young female patients (Sodergren *et al.*, 2018). According to (Metallo *et al.*, 2016), radioactive therapy does not impact pregnancy outcomes. Although many other side effects of the treatment should be carefully considered, there is no reported risk of infertility or severe genetic changes in both men (Hyer *et al.*, 2002) and women (Bal *et al.*, 2005). This is reassuring information for patients; however, some patients still worry about it, and it affects their treatment decisions.

### **Side effects related to hormones distortion**

Due to having had their thyroid removed, patients with thyroid cancer require lifelong thyroid hormone replacement therapy. However, establishing the correct dose may take some time, and people may be temporarily hypothyroid (Laura *et al.*, 2019). Hypothyroid symptoms of an inadequate dose of thyroid hormone therapy include increased appetite (Botella-Carretero *et al.*, 2003; Applewhite, James, *et al.*, 2016), sleep problems (Pelttari *et al.*, 2009; Roerink *et al.*, 2013; Rubic *et al.*, 2014; Applewhite, White, *et al.*, 2016; Singer *et al.*, 2016; Hedman, Djärv, *et al.*, 2017) including insomnia (Huang *et al.*, 2004), dyspnoea (Gamper *et al.*, 2015; Rogers *et al.*, 2017), blurred vision, dizziness and nausea (Botella-Carretero *et al.*, 2003), lack usefulness (Applewhite, James, *et al.*, 2016). However, it is also possible that some patients have symptoms of hyperthyroidism. Slight hyperthyroidism is desirable because patients with thyroid hormone suppression therapy receive higher doses of the hormone to suppress the TSH. Symptoms of hyperthyroidism include palpitation and weight loss (Schultz *et al.*, 2003).

Symptoms like sleep difficulty and weight gain are mostly correlated to decreased quality of life (Singer *et al.*, 2016). As seen, thyroid cancer patients and survivors can be faced with symptoms of both hypo and hyperthyroidism.

Other common symptoms related to hormonal distortion include intolerance to heat or cold temperature (Tagay *et al.*, 2006; Roberts, Lepore and Urken, 2008; Steel, Schmidt and Shultz, 2008; Rubic *et al.*, 2014; Duan *et al.*, 2015; Anh *et al.*, 2016) including hot flushes (Hedman, Djärv, *et al.*, 2017; Rogers *et al.*, 2017), sweating (Hedman, Djärv, *et al.*, 2017) and chills (Huang *et al.*, 2004). Other symptoms reported include weight gain (Schultz, Stava and Vassilopoulou-Sellin, 2003; Rubic *et al.*, 2014; Anh *et al.*, 2016; Rogers *et al.*, 2017), even in 31.7% of respondents (Roerink *et al.*, 2013), memory loss (Easley, Miedema and Robinson, 2013; Aschebrook-Kilfoy *et al.*, 2015), migraine headaches (Easley, Miedema and Robinson, 2013), loosing hair (Schultz, Stava and Vassilopoulou-Sellin, 2003; Aschebrook-Kilfoy *et al.*, 2015), bone issues like pain (Aschebrook-Kilfoy *et al.*, 2015), muscle weakness, bodily restlessness, palpitations (Hedman, Djärv, *et al.*, 2017), skin dryness (Schultz, Stava and Vassilopoulou-Sellin, 2003; Gómez *et al.*, 2010; Rogers *et al.*, 2017) eye dryness (Aschebrook-Kilfoy *et al.*, 2015), mouth dryness (Rogers *et al.*, 2017) and hair loss (Schultz, Stava and Vassilopoulou-Sellin, 2003). Issues related to hormone distortion but correlated with decreased quality of life are levothyroxine dose, and serum FT4 levels did not affect any areas measured in the questionnaire (Hoftijzer *et al.*, 2008).

In all phases of their treatment, patients with differentiated thyroid cancer reported an effect on cognitive functioning that impacted their activities, including work (Gallop, 2015). Patients had impairments in cognitive functioning of HRQoL compared with cancer-free controls who were sex- and age-matched. Thyroid cancer symptoms, including concentration, were the significant determinants of HRQoL (Vigário *et al.*, 2014). Participants reported various related cognitive problems, including problems with memory, problems with thinking, attention problems, decreased concentration (Husson *et al.*, 2013) and memory loss (Schultz, Stava and Vassilopoulou-Sellin, 2003). However, some of the results might be related to levothyroxine withdrawal practices that cause hypothyroidism (Burmeister *et al.*, 2001; Schultz, Stava and Vassilopoulou-Sellin, 2003; Tagay *et al.*, 2006) that took place in the UK in the past. It is important to note that there is an opinion that cognitive functioning does not impact HRQOL in patients with thyroid cancer (Gamperet *et al.*, 2015). As seen, some patients do suffer from cognitive symptoms related to hormonal distortion. However, this may be limited and does not have a detrimental effect on people's lives.

#### **2.5.4 Long-term physical side effects of cancer in general and in thyroid cancer**

It has been reported that other cancer survivors are more likely to report problems including diabetes, heart conditions, kidney problems, stroke, cataracts, arthritis/osteoporosis, and psychological issues (Schultz, Stava and Vassilopoulou-Sellin, 2003). Other long-term problems include pain, fatigue, sexual dysfunction and memory problems, and late effects, including second malignancies, osteoporosis and cardiovascular disease (Husson *et al.*, 2011). Cardiovascular disease is the primary cause of mortality and morbidity (Kochanek *et al.*, 2016). It is similar to the cancer survivor population (Bayliss *et al.*, 2014). Due to the modernisation of treatment, there are more and more living cancer survivors (Edwards *et al.*, 2014). Cancer survivors commonly deal with long-term complications and side effects of their disease, affecting their general health and wellbeing. Cancer survivors are likely to have extra difficulties in their remaining lives, but the causes of death are very similar to those of the general population.

Similarly, as thyroid cancer disease detection increases and it is a highly curable disease, there is an increasing number of thyroid cancer survivors (Schultz, Stava and Vassilopoulou-Sellin, 2003). Compared to other cancer survivors, thyroid cancer survivors are more likely to report long-term side effects like memory problems (Schultz, Stava and Vassilopoulou-Sellin, 2003; Easley, Miedema and Robinson, 2013), headaches and psychological problems (Schultz, Stava and Vassilopoulou-Sellin, 2003; Hedman, Strang, *et al.*, 2017). These side effects are not clearly understood. In this study, 64.6 % of participants stated that thyroid cancer affected their overall health. The results were more significant in women and were strongly correlated with RAI treatment. The negative perception of general health decreased with increased time of diagnosis. For men, the main problem reported was neurological, cardiovascular, genitourinary, and pulmonary. In women, musculoskeletal, gastrointestinal, psychological, and endocrinological problems were more prevalent. It is important to note that the health care professionals did not acknowledge its existence for some participants. Thus, they were not addressed (Sawka *et al.*, 2009). Moreover, lifelong thyroid hormone suppressive therapy can cause thyrotoxicosis with symptoms like, for example, palpitations, mood changes (Sawka *et al.*, 2009), osteoporosis or atrial fibrillation (Chen, Jemal and Ward, 2009). Most cancer treatments come with various symptoms, side effects and possible complications. People can be affected by the variety of symptoms that come in hand with thyroid cancer treatment.

#### **2.6 Psychological impact**

People react to a stressful event/situation differently cognitively, emotionally and behaviorally. Cognitive reactions can include the way people explain the situation to themselves. Emotional is

the way they feel about the situation or event. The behavioural reaction is the action or lack of action to respond to the situation (Parker and Endler, 1992). Similarly, coping strategies can be categorised as problem-focused and emotion-focused, with the first being more of an adaptation approach (Avero *et al.*, 2003). Coping can be done in a grow-supporting approach (Taylor and Stanton, 2007). It can be noted that some people who were facing difficulty resort to their resilience (Bonanno, 2004). Furthermore, it is not unheard of for people to experience substantial growth after a stressful and life-changing event (Peterson *et al.*, 2008).

Personality traits are hereditary (Lykken and Tellegen, 1996). Thus, genetics can impact the way people react to adverse life events. For example, an optimistic personality may be associated with more active coping strategies rather than a passive approach like denial. Active coping strategies may even lead to overcoming adverse life events. However, this situation is not always possible (Aspinwall and Taylor, 1997; Chang, 1998; Schueller, 2009).

Moreover, problem-focused coping associated with optimism has assisted recovery from surgery (Scheier *et al.*, 2003). Optimists seek solutions to their problems more actively to increase the chances of a good result (Scheier, Carver and Bridges, 2003). On the other hand, neurotic people tend to choose ineffective coping strategies (Bolger and Zuckerman, 1995). This can mean that their adaptation is slower and less effective. Another ineffective coping strategy is, for example, denial, which is also associated with neurotic and introverted personality traits (Ferguson, 2001). Pessimists spend more time thinking about the event and resort to more emotion-based strategies that are less successful than problem-focused ones (Schueller, 2009). Thus, optimism is the outlook on life that effectively improves the ability to cope with adverse events.

Psychological resilience also helps an individual deal effectively with adverse life events. People with good levels of psychological reliance are characterised by a high level of hedonic capital (Graham and Oswald, 2010). According to the authors, a good level of hedonic capital improves our psychological resilience and assists us with managing challenges in life. Individuals who went through adverse life events try to rebuild the hedonic capital used as psychological resources during the event (Graham and Oswald, 2010). Also, positive psychological traits, such as optimistic views, improve people's wellbeing. They were called 'generalised resistance resources' (Antonovsky, 1979). Wilson and Gilbert (2005) suggest that attention is drawn more to events that are difficult to explain. The authors argue that people like to explain the circumstances in their life and can cope better with the events they can explain.

### 2.6.1 Negative emotional impact: Psychological distress

Psychological Distress (PD) can be described as a period of emotional difficulty (Buchmann *et al.*, 2015) or instability (Millar *et al.*, 2005) experienced by a person in an event such as a diagnosis of cancer. It can present itself as anxiety and depression, as other psychological problems, such as difficulty adjusting (Millar *et al.*, 2005). The prevalence of even significant distress can be high in patients with cancer. For example, 46% of 4664 participants in Carlson *et al.* (2019) study experienced considerable distress (more significant in females). Nineteen patients (13.1%) wanted support from another professional to help them deal with coping. Thirty-seven patients (25.5%) said “maybe” they needed additional help. The lowest score for distress, the more likely patients were willing to use additional support (Roerink *et al.*, 2013). Although most cancer survivors have no clinical level of PD, they differ significantly in positive mental health measures. Variations in PD are because cancer patients are not homogenous (Zabora *et al.*, 2001). Thus, it is vital to screen patients to enable people in PD to access psychological help, which in turn may improve their wellbeing (Mitchell, 2013). Moreover, people may be reluctant to ‘bother’ doctors with emotional or minor health issues (Duan *et al.*, 2015). Overall, PD seems to be present in oncological patients, but it is highly variable among individuals with cancer.

Distress in patients with thyroid cancer is present despite the excellent prognosis. In patients newly diagnosed with thyroid cancer, high levels of distress can be observed (Aschebrook-Kilfoy *et al.*, 2015; Buchmann *et al.*, 2015; Rogers *et al.*, 2017). When looking at the levels of psychosocial distress in thyroid cancer patients, (Buchmann *et al.*, 2015) observed that 24 patients (out of 118) reported experiencing no distress. Almost half of the participants (43.3%) had experienced significant distress. Furthermore, distress is prevalent in patients with thyroid cancer even if a long time has passed without recurrence (Roerink *et al.*, 2013). In this study, 34.3% of participants reported a high level of distress requiring intervention in practice. Significantly, it has been reported that local recurrence has a (significant) impact on distress levels (Misra *et al.*, 2013). Even though thyroid cancer has an excellent prognosis, the distress expressed by some patients is significant and can have a detrimental effect on their experience.

Interestingly, the prevalence of distress cannot be predicted by clinical (no correlation between the duration of follow-up or the TSH levels and depression scores) and demographic factors except for employment status (participants with part-time or full-time employment reported significantly less distress, which is currently unexplained) (Roerink *et al.*, 2013). Participants reported physical (86%) and emotional (76%) causes of distress. Other causes of distress reported in the literature are related to treatment with iodine ablation and surgery (Aschebrook-

Kilfoy *et al.*, 2015). Factors predicting high levels of distress were sadness, nervousness, history of radiation, problems getting around (regarding mobility), nervousness, fatigue, and use of antidepressants (Roerink *et al.*, 2013). The extent of and intensity of distress are not related to clinical measures not demographic factors but rather to the presence of some negative emotions, preexisted mental health issues and treatment type, especially RAI.

### **2.6.2 Anxiety and depression**

Anxiety is well-established in the literature as an issue for patients with cancer, both cured and with metastasis or recurrence (Stark and House, 2000; Carlson *et al.*, 2004; Gutkin *et al.*, 2019; Maillet *et al.*, 2019). Thyroid cancer patients commonly experience anxiety and depression many years after the treatment (Choi *et al.*, 2019; Dionisi-Vici *et al.*, 2021). Moreover, depression can be linked to poor adherence to treatment. It can affect prognosis (Arrieta *et al.*, 2013) and all-cause mortality ten years after diagnosis (Mols *et al.*, 2013). For some patients with cancer, anxiety issues decrease with time, while for others, anxiety disorders may persist or even escalate with time (Alfonsson *et al.*, 2016). However, many patients do not need extra support related to their anxiety. They can cope with health care providers' legal support and social and family circles (Carlson *et al.*, 2004).

Subsequently, anxiety and depression can be linked to thyroid cancer in only some people but in all phases of treatment (Gallop *et al.*, 2015). There is evidence of anxiety and depression in the thyroid cancer population, even long-term anxiety (Crevenna *et al.*, 2003; Tagay *et al.*, 2006; Hoftijzer *et al.*, 2008; Husson *et al.*, 2011; Easley, Miedema and Robinson, 2013; Singer *et al.*, 2016). Overall, however, it seems that the link between thyroid cancer and anxiety in depression is not reliable. For example, in Gómez *et al.* (2010) study (descriptive correlational methodology), only 2.7 % (out of 75 participants) of participants experienced high levels of anxiety, while 40% had no anxiety related to their disease. Similarly, 33% of participants experienced no depression, and only 4% reported high feelings of depression. Rogers *et al.* (2017) reported anxiety levels at 27% and depression (at 18%). Giusti *et al.* (2011), in their 5-year longitudinal quality of life evaluation study, observed significant changes in time related to anxiety and depression. However, there was a considerable variation between participants.

In another example, Tagay *et al.* (2006) reported significantly lower scores in physical and mental health and increased prevalence of anxiety (but not depression) in people with thyroid cancer compared to the general German population. In the study, distress parameters were in normal and not significant ranges. 9% (out of 136) of patients had borderline depression, while 8% of patients as having definite depression. Anxiety results were borderline (37%) and explicit

(26%). The authors did not give details of anxiety levels in the general public but provided a reference that the author could not access. However, if we compare the UK statistics from the Office of National Statistics, in 2014, the prevalence of anxiety or depression in general populations was 19.7% (Evans, Macrory and Randall, 2016). Tagay *et al.* (2006) study looked at parameters during the pre-ablation phase of the treatment when the thyroid hormone was still being withdrawn. People were in a state of hypothyroidism, which has well reported a negative effect on people's lives. Currently, due to the use of rhTSH, patients are spared the hypothyroidism effect in this phase of the treatment. However, it is worth mentioning here as it has been reported that the state of hypothyroidism is still prevalent in thyroid cancer survivors and can happen years after diagnosis (Livhits and Yeh, 2017). Also, some patients with thyroid cancer had a prior diagnosis of hypothyroidism before thyroid cancer was detected (Hung, Chung and Lin, 2018). As seen above, the studies showed a link between anxiety and depression and thyroid cancer. It is relevant for some people more than for others.

It is worth noting that depression or anxiety may be unrelated to thyroid cancer in some patients anxiety in the general population is relatively common (Haller *et al.*, 2014), with 1 in 14 people globally having an anxiety disorder. In Lubitz *et al.* (2017) study, 27% had a previous diagnosis of anxiety and depression out of 117 patients. It is important to note that research showed that untreated underlying depression could affect overall survival (Onitilo, Nietert and Egede, 2006; Holland and Alici, 2010). Moreover, people with anxiety and depression pre-diagnosed with thyroid cancer were significantly more at risk of experiencing high levels of distress in thyroid cancer diagnosis and treatment. A similar correlation was found for the participant with a previous diagnosis of the psychiatric problem (Buchmann *et al.*, 2015). Consequently, the pre-existence of anxiety and depression amplifies the risk of adverse psychological challenges during the thyroid cancer journey.

The presence of anxiety and depression affects the quality of life. Anxiety in thyroid cancer negatively influences lives and all dimensions of wellbeing, including physical, social, emotional, and cognitive functioning (Lee *et al.*, 2010). Using multiple regression data from multiple sources, the authors determined that anxiety, depression, and fatigue were the strongest determinants in all domains in the EORTC and QLQ-C30 questionnaires. Another author agrees that higher anxiety levels correlate to a lower quality of life (Taïeb *et al.*, 2009). However, mood disorders and anxiety also impact the quality of life. Depression was highly connected to hypothyroid thyroid cancer patients' poor physical and psychological quality of life (Tagay *et al.*, 2006).

Moreover, depression affects global health, role and cognitive functioning (Lee *et al.*, 2010). Mental exhaustion is related to depression, which affects people (Singer *et al.*, 2016). It seems

thyroid cancer can increase the risk of anxiety and depression, negatively impacting the quality of life.

The sources of anxiety in people with thyroid cancer can be varied (Hedman, Strang, *et al.*, 2017) has undergone an in-depth exploration of anxiety, sources of anxiety, and protective strategies. Respondents expressed fear and worries about their current situation and possible future risks. The anxiety felt was vague by some but intense by other respondents, even causing physical psychosomatic symptoms. The anxiety was rising in intensity around the time of tests and decreased when no new findings or recurrences were found. Follow-up appointments also provided more anxiety. One participant expressed she felt a "little anxious", while other participants showed that the fear was "extreme". When there was thyroglobulin in the blood, another point was that anxiety was intensified. Other reasons for anxiety were distrust of the health care system, fear of recurrence being missed, lack of continuity of care, and communication issues like vague and evasive answers to questions. One participant mentioned that driving next to the hospital is a distressing experience (Gallop *et al.*, 2015). The anxiety is related to treatment and appointments and other factors like the future and ranges in intensity in different people and situations.

### **2.6.3 Diagnosis reaction, Fear of Recurrence and Other Concerns**

Patients differ in their reaction to receiving the diagnosis of thyroid cancer. Although the doctor says: "You have a carcinoma with an extremely favourable prognosis", the patient does not, as expected by the doctor, concentrate on the favourable prognosis part of the statement. On the contrary, patients hear the word cancer or carcinoma, which induces fear (Duan *et al.*, 2015). Other reported diagnoses' reactions include shock, disbelief, devastation (Anh *et al.*, 2016) and stress (Husson *et al.*, 2013).

One participant from Anh *et al.* (2016) study was told they had carcinoma; they had to google it at home and found out they have cancer. For most participants, the diagnosis of thyroid cancer is a life-changing and scary event. The quality of life scores was observed for the initial diagnosis's distress (Applewhite, James, *et al.*, 2016). Even though participants were aware of low mortality figures for this type of cancer, the diagnosis still provided feelings of fear and uncertainty. Participants expressed that the label 'good cancer', often used by media and healthcare professionals, is not reassuring (Sawka *et al.*, 2009). In theory, the good prognosis and cure rates should reassure patients. However, in practice, people are terrified and uncertain of being diagnosed with thyroid cancer.

Fear of recurrence is one of the more commonly reported concerns in oncological patients, and it is universal for all cancer types (Koch-Gallenkamp *et al.*, 2016; van de Wal *et al.*, 2016; Cohee *et al.*, 2017), especially in young adults (Crist and Grunfeld, 2013; Lane *et al.*, 2019). Fear of Recurrence is one of the most distressing emotions in the cancer journey (Härtl *et al.*, 2003). It has a prominent adverse effect on the quality of life and PD (Koch *et al.*, 2013). Fear of getting cancer is prevalent even in the general population. It could be due to our preconceived perception of disease (Vrinten *et al.*, 2017). Diagnosis of any cancer is a scary situation. Even after the cancer is cured, the possibility of it returning lingers in people's minds, affecting their lives.

Many studies have suggested that fear of recurrence is a common concern among patients with thyroid cancer and survivors (Roberts, Lepore and Urken, 2008; Aschebrook-Kilfoy *et al.*, 2015; Gallop *et al.*, 2015; Singer *et al.*, 2016; Hedman, Strang, *et al.*, 2017; Lubitz *et al.*, 2017; Maria Papaleontiou *et al.*, 2019), even as long as 15 years after initial diagnosis (Rogers *et al.*, 2017). Some authors report modest overall levels of fear (Roberts, Lepore and Urken, 2008), while others said that for some patients, it could be severe (Rogers *et al.*, 2017). One illustration of this is that 1 in 7 patients responded that they had “many fears of recurrence that preoccupied their thoughts” or were “fearful all the time that their cancer might return and that they struggled with this”. However, 35% responded and expressed that they occasionally experience manageable fearful thoughts. For 10-10% of others, the experience of fear was shown as "a lot" (10%) or "all the time" (19%). Psychological distress can be affected and worsened by fear of reoccurrence. Even though patients have an excellent prognosis, almost half of patients are worried about the reoccurrence of thyroid cancer (Rogers *et al.*, 2017). For many people with thyroid cancer, fear of recurrence is a common and distressing part of the thyroid cancer journey.

It is important to note that patients with reoccurrence and those experiencing fear of reoccurrence report lower quality of life. Furthermore, the effect on their quality of life was very similar in both groups (Hedman, Djärv, *et al.*, 2017). In their questionnaire-based study of 279 participants, only 7% of patients had a reoccurrence, but 48% were worried about it happening. Furthermore, 11% of respondents admitted that thyroid cancer gave them a negative outlook on life. They have also reported more reduced quality of life. Fear of recurrence has a similar effect on wellbeing to having an actual recurrence. Thus, it is essential that it is recognised and acted upon.

Fear of recurrence is not the only source of worry for people with thyroid cancer. In Buchmann *et al.* (2015), thyroid cancer survivors experience worrying (50% out of 118), being nervous

(49.2%) and fear (36.4%). Sources of concern and worry for people with thyroid cancer are metastases and getting other types of cancers as well as overall outcomes (Aschebrook-Kilfoy *et al.*, 2015; Hedman, Djärv, *et al.*, 2017). Some patients worry about necessary future treatment, appointments and RAI treatments (Gallop *et al.*, 2015), hair loss (Duan *et al.*, 2015; Gallop *et al.*, 2015), and general fear of diagnosis and treatment (Sawka *et al.*, 2009), its side effects (Sawka *et al.*, 2009; Duan *et al.*, 2015; Maria Papaleontiou *et al.*, 2019) and complications (Lubitz *et al.*, 2017), death (Hedman, Strang, *et al.*, 2017; Maria Papaleontiou *et al.*, 2019), changes in lifestyle related to treatment (Lubitz *et al.*, 2017; Maria Papaleontiou *et al.*, 2019), thyroid hormone replacement therapy, prognosis (Lubitz *et al.*, 2017), lack of sufficient information (Hedman *et al.*, 2016) second operation (Singer *et al.*, 2016), putting their family at risk (Maria Papaleontiou *et al.*, 2019). Some young female thyroid cancer patients and survivors reported being worried about the ability to become a mother in the future. It is associated with decreased quality of life (Singer *et al.*, 2016; Sodergren *et al.*, 2018). Other concerns for patients with thyroid are worried about the perception of thyroid cancer as not serious (Sawka *et al.*, 2009). Some patients reported a general feeling of uncertainty (Sawka *et al.*, 2009; Aschebrook-Kilfoy *et al.*, 2015; Hedman, Strang, *et al.*, 2017). Especially, uncertainty was persistent in participants with current and persistent diseases (Hedman, Strang, *et al.*, 2017). Thyroid cancer causes a variety of negative emotions, fears, concerns and stress.

#### **2.6.4 Isolation from other cancer patients**

Moreover, because thyroid cancer is unique in terms of treatment and characteristics, it can impact feelings of alienation from other oncological patients. Easley, Miedema and Robinson (2013) looked at the concept of isolation in young thyroid cancer patients. They looked at isolation from patients with other types of cancer and support programs, the isolation during RAI treatment, and isolation from their friends without cancer. Concerning isolation from patients with other cancers, participants felt difficulty relating to them. The authors felt that the other patients did not want to acknowledge their experience as the side effects of TC treatment is not as severe as their own. The age of other patients with cancer was also a contributing factor. Isolation from peers was expressed as a lack of common understanding as other young people had never experienced a severe disease. Some of the peers expressed a carefree attitude to their friend's disease and that this is distressing. Feelings of isolation reflect the hospital stay and isolation from other cancer patients and friends, which is related to being misunderstood. Consequently, patients may feel alienated from other cancer patients and misunderstood by health care professionals. Although isolation is a significant problem when receiving RAI, relationships with others are not necessarily a supportive factor. They have to be a good relationship to impact experience positively.

## 2.7 Relationship with people

Emotional health depends on the level of integration of individuals in their social environment (Rose, 2000). Putnam (2020) two decades earlier established four areas of social capital: trust, civic engagement and participation, social networking, shared norms or reciprocity. We create a variety of interactions and relationships in our life (Bagnall *et al.*, 2017). The most important part of social capital is the family (Putnam, 1995), and the quality of relationships is pivotal (Putnam, 2020).

Good social support enhances good habits and behaviour, while lack can lead to unhealthy behaviours (Ståhl *et al.*, 2001). In times of disease or adverse events, women tend to turn to family and friends. Men, however, are more likely to turn to bad habits like alcohol instead of relying on their social capital support (Ståhl *et al.*, 2001). Interestingly, socio-economic inequalities affect social relationships (Friedli, 2009). Putnam (2020) argues that high levels of social capital are linked to reasonable levels of health and happiness. The author claims that social capital can prevent physical and mental diseases and aid recovery from the disease. Improvements in health can be achieved with the help of community, family and networks of friends (Berkman *et al.*, 2000). Interventions that aim to improve the community and social capital are linked to improved health outcomes (Marmot and Bell, 2012).

### 2.7.1 Relationship with family and friends

Relationships with friends and family and their support are essential for patients with thyroid cancer and have an impact on their wellbeing (Huang *et al.*, 2004; Sawka *et al.*, 2009; Gallop *et al.*, 2015; Singer *et al.*, 2016). Family and friends can be a vital source of psychological support for patients, even though they may not be well informed regarding the disease itself (Sawka *et al.*, 2009). Furthermore, having a partner improves the quality of life and decreases levels of anxiety and depression (Taïeb *et al.*, 2009). People who never married report more health issues than married patients (Schultz, Stava and Vassilopoulou-Sellin, 2003). However, Hoftijzer *et al.* (2008) argue that marital status is not correlated to decreased quality of life. Some study participants report not having good support from family (Rozema, Völlink and Lechner, 2009; Aschebrook-Kilfoy *et al.*, 2015; Gallop *et al.*, 2015; Applewhite, James, *et al.*, 2016) and experiencing a lack of understanding (Gallop *et al.*, 2015). Family and friends are essential sources of support and comfort for patients with thyroid cancer. However, not all patients have that strong family support. It is especially the case for people without a partner.

The diagnosis and treatment of thyroid cancer in participants can cause much distress to their family members (Aschebrook-Kilfoy *et al.*, 2015) and cause other family problems (11%) (Buchmann *et al.*, 2015). For example, people worry about their children, about their children becoming orphans (Duan *et al.*, 2015; Gallop *et al.*, 2015) and about being separated from their children during treatment (Harding, 2016). Some people reported being tired and having less energy to engage with their children (Gallop *et al.*, 2015). People may also worry about being a family burden (Singer *et al.*, 2016). Some authors reported that participants in all treatment stages complained that their relationships were negatively affected but their cancer (Gallop *et al.*, 2015). Participants in another study reported pressures in their relationships. One participant stated that their partner was more worried that they were of recurrence. Another reported relationship breakdown with diagnosis and treatment being a final strain on the relationship (Anh *et al.*, 2016). Some participants are worried about dating, being treated differently, and being scared of people's reactions (Gallop *et al.*, 2015).

On the other hand, going through a cancer journey may improve relationships. It could result from positive personal and social adaptation after the traumatic event. It was the case for 43.4% of participants. On the other hand, 1.6% of participants reported damage to the relationship 57.1% reported no changes in their family relationship (Schultz, Stava and Vassilopoulou-Sellin, 2003). In some people, thyroid cancer can affect relationships in negative and occasionally positive ways.

### **2.7.2 Relationships with Health Care Professional (HCP)**

The management of thyroid cancer is multi-disciplinary, combining the efforts of surgical, oncological, and nuclear medicine. The fact that a patient is taken care of by many teams can have effects on patients in many ways (physical, social and psychological (Singer *et al.*, 2016). It also means that the relationship with HCPs is a big part of the thyroid cancer journal and vital for quality of life (Gallop *et al.*, 2015; Singer *et al.*, 2016). Most participants in studies on the topic spoke very highly about HCP involved in their care. They were perceived as providing "enormous" help.

Moreover, personal touches are valued (Anh *et al.*, 2016). Nurses could play an essential part in enhancing the quality of life for these people by educating them in effective management of their symptoms and supporting them in strengthening their social support (Huang *et al.*, 2004). Health care professionals are an essential source of support. However, a lack of support from doctors is sometimes reported in studies. For example, 33.8% of participants felt unsupported by their care team (Aschebrook-Kilfoy *et al.*, 2015; Applewhite, White, *et al.*, 2016).

Relationship with health care providers is one of the vital aspects of the cancer journey that can positively affect people's lives.

### **2.7.3 Good cancer phenomenon**

Papillary thyroid cancer is often labelled the “good cancer” because of its favourable prognosis, and patients newly diagnosed with thyroid cancer frequently encounter this perspective. Most patients have reported being told they have good cancer (Tagay *et al.*, 2006; Sawka *et al.*, 2009; Husson *et al.*, 2011; Costa and Pakenham, 2012; Anh *et al.*, 2016). Patients encounter “good cancer” perspectives from multiple sources, including internet research, friends and loved ones (Easley, Miedema and Robinson, 2013; Randle *et al.*, 2017). Some participant says they have good cancer based on their understanding. For example, one participant was told by HCP, “it is no big deal because this is very easy to cure.” Alternatively, “if you have to have cancer, this is the best one to have.”

One study investigated how the concept of thyroid cancer as the “good cancer” affected patients' experience with this disease. Although this perspective often evoked feelings of reassurance (Easley, Miedema and Robinson, 2013; Anh *et al.*, 2016; Randle *et al.*, 2017), many patients experienced negative feelings like invalidation and confusion significantly when their experiences varied from expectations (Easley, Miedema and Robinson, 2013). Moreover, for some people, good cancer perception was perceived as not giving justice to the disease, risk of death, and various symptoms and complications (Anh *et al.*, 2016). For some people with thyroid cancer, being told they have good cancer was a paradox. It made them feel unworthy of support. Even though thyroid cancer patients have no chemotherapy and its side effects, their cancer is still life-threatening. Treatment consequences and side effects may not be visible but are prevalent in many survivors (Easley, Miedema and Robinson, 2013). Good cancer is unfair. Many survivors suffer a long-term and significant decrease in quality of life. Side effects are complications are well documented. However, good cancer stigma is still prevalent in society and among health care providers (Randle *et al.*, 2017). Treating thyroid cancer as good does not justify the struggles and challenges that this disease and treatment brings.

Moreover, physicians tend to underestimate the prevalence of physical symptoms in thyroid cancer patients. Over half of the study's physicians reported that they tell patients that they have a “good cancer” (James *et al.*, 2018). Medical professionals underestimate another aspect of thyroid cancer's impact on life, including financial impact. This dissociation in patient and doctor perspectives can lead to suboptimal quality of care delivered. This, in turn, can negatively affect the quality of life (James *et al.*, 2018). Patients value HCPs' opinions

about their condition (Sawka *et al.*, 2009).

Nevertheless, this attitude makes patients feel like they are not being taken seriously (Sawka *et al.*, 2009 and they could like to change it (Anh *et al.*, 2016). Randle *et al.* (2017) recommends avoiding the terminology of a good cancer as it strips the value of people's experience of cancer. Patients must create the meaning of their cancer. It creates a gap between what clinicians think about the disease and what patients think about it as they experience it.

## **2.8 Working life and thyroid cancer**

Because thyroid cancer affects the younger population, many patients are actively working. 63% of participants in (Schultz, Stava and Vassilopoulou-Sellin, 2003) were employed during the thyroid cancer, 7% said that due to the disease, they could not work. In another study, a cross-sectional population-based enquiry, out of 223 participants, 71% were employed. However, 33 % of participants reported cancer-related changes to their work, for example, working fewer hours, being fired, being disabled, and being stopped working or early retirement (Tamminga *et al.*, 2016). In a more recent study, 12.3% of survivors do not return to work five years following TC diagnosis (Creff *et al.*, 2021). Unemployed thyroid cancer survivors were more correlated with older age, lower educational level (more chance of unemployment), higher level of fatigue, later cancer stage, depression, anxiety, and one or more comorbidities.

Marital status, gender, the treatment or type of tumour were not related to not having employment. Unemployed people experience worse overall quality of life (Gallop *et al.*, 2015; Singer *et al.*, 2016). Thus, fatigued, older and lower-educated thyroid cancer survivors are more likely to be unemployed, negatively impacting their financial situation and quality of life (Gallop *et al.*, 2015). On the contrary, other authors concluded that younger people are more at risk of employment and financial troubles during and after cancer (Mehnert, 2011; Peat, Rodriguez and Smith, 2019). Employed patients tend to have better role-physical emotional domains (Husson *et al.*, 2011), as well as less distress (Roerink *et al.*, 2013) compared to their counterparts (Lee *et al.*, 2010). Surprisingly, Huang *et al.* (2004) argued that work status was not correlated with quality of life. However, as presented above, more authors disagree with this conclusion.

## **2.9 Finances and Thyroid Cancer**

Thyroid cancer treatment may affect people's financial situation adding to the emotional and physical burden of the disease (Gallop *et al.*, 2015; James *et al.*, 2018). Besides psychosocial

and physical challenges, financial difficulties are more familiar with thyroid cancer than other malignancies (Ramsey *et al.*, 2013). A recent study reported that 61.6% of participants indicated income decline within five years of diagnosis of thyroid cancer (Creff *et al.*, 2021). Moreover, some respondents reported difficulties obtaining life insurance and mortgage. Out of people who reported problems with a mortgage, more than half were rejected (Tamminga *et al.*, 2016). Other reasons for the financial impact of TC are travel costs to attend doctor's appointments, the cost of medication (in the US) and issues with health insurance (Gallop *et al.*, 2015). In addition, thyroid cancer patients have a higher bankruptcy rate than other cancers (James *et al.*, 2018). It could also be because thyroid cancer patients are younger than representatives of other cancers. Moreover, literature has reported that young people with cancer tend to have more financial and employment problems (Gallop *et al.*, 2015; Singer *et al.*, 2016). Although some participants may be affected financially by their disease and its implication, there was no effect of a financial burden on their quality of life (Roberts, Lepore and Urken, 2008).

## **2.10 Summary of the chapter**

Overall, these findings challenge the assumption held by many that thyroid cancer is good cancer. Previous research suggests that people's lives are strongly affected. It can be reassuring that for most people, the adverse effects are diminishing with time or can even turn into long-term positive changes. However, for some patients, physical symptoms can persist for years after treatment affecting their quality of life. The quality of life of thyroid cancer survivors is comparable to the welfare of people with other cancers, and the literature suggests that one of the reasons may be inequalities in cancer support provision and recognition of thyroid cancer. It is also clear that fear of recurrence is not related to prognosis and more to the fact that thyroid cancer is indeed cancer. Thus, the patient having thyroid cancer should be treated with adequate seriousness regarding their disease.

Treatment has a significant impact on patients' lives. Surgery temporarily affects the quality of life. However, in most cases, with time, it goes back to normal levels. Quality of life is not related to the type of surgery but rather the quality and severity of side effects. Post-surgical scarring can be problematic for some. It can be painful and uncomfortable, especially initially.

Moreover, it can cause body image problems, especially in young female patients. Another treatment phase, radioactive iodine ablation, can temporarily impact the quality of life. Patients' quality of life seems to be similar, whether they had that treatment. However, RAI is a cause of worry, physical side effects and isolation. Hormone therapy is the phase of the treatment that lasts for the rest of the lives of most patients (those with total thyroidectomy). The quality of life

seems to be affected when the hormonal imbalances cause problems like fatigue, irrespectively to serum THS results.

Being diagnosed with thyroid cancer had a detrimental effect on individual mental and psychological quality of life. Despite a good prognosis in most cases, the distress is very prevalent. It has its' causes in both physical and emotional domains. Physical causes include side effects and symptoms, as well as overall tiredness affecting people's lives. Emotional aspects include distress, anxiety, and concerns, including fear of recurrence and death. Although the link between thyroid cancer and depression is not significant, if present, it amplifies detrimental psychological effects on lives.

Patients with thyroid cancer perceive their disease as serious. Many patients suffer from various physical ailments and comorbidities, but generally, their overall health is good. Thyroid cancer patients tend to be a little younger than most of the oncological population. Thyroid cancer carries implications in the form of physical symptoms, treatment side effects and occasional more severe complications. Most of the problems resolve and are temporary. However, some turn out to be present for years or even permanently. Challenges are related to all parts of the treatment, including surgery, iodine therapy and hormonal therapy. Some levels of pain are also commonly related to surgery and iodine ablation. Fatigue is one of the most reported problems. It, as well as other physical challenges, can affect daily living.

Family and friends are essential sources of support and comfort for patients with thyroid cancer. However, not all patients have that strong family support. It is especially the case for people without a partner. In some people, thyroid cancer can affect relationships in negative and occasionally positive ways. For some people, the disease did not change their relationships. Relationship with health care providers is one of the vital aspects of the cancer journey that can positively or negatively affect the whole experience.

The current findings from the literature explain that the perception of good cancer is unfounded. People that go through the diagnosis and treatment for thyroid cancer experience several adverse challenges and hurdles, including physical, social, psychological, and spiritual changes. Treating thyroid cancer as good does not justify the struggles and challenges that this disease and treatment brings. It seems like the term good cancer might have created a level of underestimation of the severity of side effects and the impact of the disease in general.

It seems that, for some people, being included in the decision-making process is more important than others. However, patients should always be aware that they can have more input into the decision-making if they wish. Most patients are pretty satisfied with the information they are

being provided. However, there are areas of the thyroid cancer journey that should be more addressed when providing patient information, including long-term effects, possible effects, emotional aspects, and practical aspects like financial. As seen above, being informed about all aspects of the disease, treatment and long-term implications is very important for patients. Online information quality in the UK is not assessed at present.

The results show that some demographic aspects impact experiencing adverse life events in people with thyroid cancer. For example, older people suffer more than average. Similarly, some younger adults may suffer more than average. Overall, younger or older females are at increased risk of impacted quality of life. Moreover, women are more prone to increased emotional impact than men.

### **2.11 How this research will add to existing literature and evidence-base**

The literature strongly suggests that thyroid cancer is a significant, life-threatening event that affects human experience on many levels. Distress experienced by patients with thyroid cancer should not be underestimated and looked at from a high survival rate perspective. The thesis presents a scoping review of current knowledge on thyroid cancer, the treatment experience, and the quality of life of people with thyroid cancer. Most of the studies were quantitative. This research discussed in this thesis added to the existing knowledge as it looked at the accounts of the lived experience of people with this cancer. It looked more carefully at what participants said about their experience, what issues they raised about their experience and what factors affected it. Most studies either measured overall quality of life or looked at one or a small number of factors. This study generated factors from participants' descriptions, gaining insight into both experiences of thyroid cancer and treatment and factors affecting their lives during treatment that is important for participants.

In the next chapter, the methodology is presented for this research study to produce results that supplement and enhance the current understanding of lived experiences in thyroid cancer.

## **Chapter 3 Methodology**

### **3.1 Overview of the chapter**

The purpose of this chapter is to provide a detailed account of the methods applied to this study. The aim and objectives, participant identification and recruitment process are described. Issues regarding ethical considerations are presented, and management of the risks is discussed. It is a qualitative, descriptive phenomenological study using mainly interviews as a method of data collection and descriptive phenomenological data analysis as well as an element of content analysis.

#### **Aims and objectives**

The study aims was to explore the lived experiences of adults diagnosed with well-differentiated thyroid carcinoma. The first objective was to use qualitative methods to explore the experiences of thyroid cancer patients – from diagnosis to recovery – from the patient's perspective. Another objective was to explore specifically the impact of hospital care and treatment. The third objective was to identify the most important factors that positively and negatively affect lived experience. Furthermore, the final objective was to make recommendations for improvements to practice in the care of thyroid cancer patients. This chapter demonstrates how the methodology and methods used achieved these objectives

### **3.2 Study design**

#### **3.2.1 Qualitative enquiry**

‘The basis of qualitative research lies in the interpretive approach to social reality and the description of the lived experience of human beings’ (Holloway and Galvin, 2017). Qualitative research is a method of study that involves the exploration of human experiences in many contexts. ‘Qualitative research is the type of research that finds out about people’s experiences, it helps understand what is important for people’ (Silverman, 2020) pp.3. Qualitative research’s strength is in understanding the perspectives of individuals as they are the focus of quantitative enquiry. With qualitative research, events or experiences can be seen through other people's eyes(Bryman, 2000). Most research in the area of lived experience in thyroid cancer is quantitative. A few qualitative studies concentrate on one aspect of life with thyroid cancer. Thus, this study is in a unique position to explore the lived experience of people as they

describe it from their perspective.

## **Phenomenology**

Phenomenology allows the generation of ‘living knowledge ‘that helps us learn from the experiences of other people’ (Neubauer, Witkop and Varpio, 2019). Phenomenological philosophers like Husserl, Heidegger, Merleau-Ponty, and Gadamer, among others, did not develop a research methodology. However, their work was used by researchers to develop a qualitative methodology (Fleming, Gaidys and Robb, 2003). Thus, phenomenology is both methodology and philosophy (Bryman, 2017). The primary division in phenomenological scholarship is between descriptive and interpretative phenomenology. This study uses a descriptive approach.

### **Giorgi descriptive phenomenology**

‘The scientific method is descriptive because its point of departure consists of concrete descriptions of experienced events from the perspective of everyday life by participants.’ (Giorgi, 2004). Phenomenology is used to understand how given phenomena present themselves in the participant's consciousness (Giorgi, 2004). Descriptive phenomenology deals with the meanings of lived experience as opposed to interpretative phenomenology, which deals with lived experience interpretations (Polit and Beck, 2004).

Giorgi's phenomenology is based on Husserl's phenomenology. Giorgi has a human science approach to phenomenology. He believes actual phenomena can only be described directly from real-life descriptions of consciousness (Hultgren, 1944). Giorgi influenced the creation of theories in nursing, for example, Watson's 1985 theory of caring. Also, Benner's middle-range theory of novice to expert was influenced heavily by phenomenology (Lawler, 1998). Recent nursing research using Giorgi's phenomenology includes (Alshawish, Qadous and Yamani, 2020).

### **Content analysis**

Initially, the researcher wanted to use only descriptive phenomenology. However, due to the very detailed and systematic data collected with the help of NVivo, the researcher decided to use a content analysis method to identify and quantify repeated factors that appear in participant descriptions. This method was also helpful in identifying which factors were the most common among participants). Content analysis is a systematic method of identifying factors in data sets, for example, interview transcripts (Harding, 2019). Moreover, although qualitative research is

more concerned with data quality than quantifying it, some counting in identifying themes and repeated factors are possible (Bryman, 2017). The content analysis differs from other descriptive analyses due to the quantitative nature of this approach (Vaismoradi, Turunen and Bondas, 2013). In addition, the content analysis aims to conceptually describe the phenomena (Elo and Kyngäs, 2008).

The researcher created a set of tables (a small example is presented in appendix 2 on page 203). Furthermore, the author mapped all identified factors for each participant using original coding from NVivo. The table gave information about how many times each factor was identified and which factors were identified for each participant. Results from this analysis were presented at the end of Result chapter 4 on page 150. The whole table was not included in the appendix due to its substantial size, but the small exemplary part can be seen in Appendix 2 on page 198.

### **3.2.2 The Researcher's philosophical stance**

The paradigm that underpins the research is constructivism. While positivism claims that reality is objective, out there and can be measured, constructivism assumes that individuals construct reality, and it can differ from person to person (Polit and Beck, 2022). The researcher believes that reality is subjective, which would be different for two people living in the same circumstances. Constructivism looks more at individual people and their constructions rather than group (Robson and McCartan, 2016). Moreover, understanding another person is not possible entirely as there is no direct access to another person's reality (Robson and McCartan, 2016). We can gain insight into somebody else's reality using qualitative data collection methods, for example, in-depth interviews. Meaningful description in descriptive phenomenology allows the researcher to understand the phenomenon in question (Howell, 2013).

From the researcher's perspective, the researcher is balancing between an insider and outsider position in the study. As a healthcare provider, the researcher is an insider and understands the needs and challenges of patients undergoing various treatments. The researcher used their insider role to assist the enquiry while being very careful that conclusions arose from data and not from their assumptions arising from their work. However, the researcher is also an outsider, as never having experienced a significant health issue, it is impossible to understand that lived reality fully.

**Table 3.1 Summary of the philosophical underpinning of this study**

<b>Terms</b>	<b>Definition of terms and references</b>	<b>The stance of this study and the researcher</b>
<b>Philosophical paradigm</b>	‘A theoretical framework (pattern, model) of reality recognised by a community of scholars. (Holloway and Galvin, 2017) pp.346	Constructivism (naturalistic approach)- the reality is based on subjective reality (Polit and Beck, 2004). It is constructed by individuals (Polit and Beck, 2022)
<b>Research philosophy</b>	Researcher’s epistemology, ontological, and methodological premises. (Denzin and Lincoln, 2008)	Qualitative research tradition
<b>Ontology</b>	Nature of reality and existence (Gutmann, 2014)	Reality is internal to the subject, and reality appears in an individual’s consciousness
<b>Epistemological assumptions</b>	‘Epistemology is the theory of knowledge and is concerned with what counts as valid knowledge.’ (Holloway and Galvin, 2017) pp.21	The researcher takes the stance of a separate physical being to minimise (not avoid) bias. The researcher attempts to understand the phenomena using a meaningful description. The researcher uses reflexivity and a natural attitude (see page 89 and 90) throughout the research process.
<b>Methodologies</b>	The way to obtain knowledge (Polit and Beck, 2004)	Descriptive Phenomenology
<b>Methods</b>	Techniques of data collection and analysis  (Robson and McCartan, 2016)	In-depth semi-structured interviews with individuals.  Data analysis is based on Giorgi’s descriptive phenomenological data analysis method.  Content analysis method

Part of the philosophy of qualitative research is that it is inevitably a subjective process. However, the researcher took steps to ensure this subjectivity did not become biased (see ensuring trustworthiness on page 90).

### **3.2.3 Justification of chosen study design**

The researcher chose to explore the phenomenon of the experience of thyroid cancer with a qualitative approach using descriptive phenomenology design to gain a detailed understanding of subjective experience after an adverse life event of being diagnosed with well-differentiated thyroid carcinoma. It is a unique study in this area.

A qualitative methodology was used for this study to address the question of the experience of going through thyroid cancer. Qualitative research allows the investigation and exploration of patients' lived experiences and factors that affect those experiences. Previous research has suggested that the quality of life of people with thyroid cancer is comparable to more aggressive forms of cancer. This study explores the patient's perspective to explain why this is the case.

Qualitative enquiry using a phenomenological study design is the method used to explore lived experience as it gives a subjective point of view of the feelings, reflections and descriptions of the events of people directly affected by the disease.

Most previous studies have used questionnaires, which is consistent with their quantitative approach, but the author used semi-structured interviews, and the next section will show why they fit well with the methodological approach. The researcher chose descriptive phenomenology as opposed to interpretative phenomenology. A descriptive phenomenology is a subjective approach using a 'phenomenological approach', whereas 'bracketing' is a method of putting aside the pre-existing assumptions of the researcher (Howell, 2013). As such, the results will give a direct voice to participants about the meanings they attach to their experience. Phenomenological enquiry is interested in establishing the essence of the experience in order to understand the phenomenon of interest (Holloway and Galvin, 2017).

### **3.3 Data collection methods**

Specific data collection methods used in this research study are discussed.

#### **Interviews**

Interviews are a standard qualitative methodology used to generate rich information about the phenomena studied. However, interviews enable the researcher to gain the topic's meaning through language. At the core of interviewing lies a deep interest in understanding the lived experience of other people and establishing meaning in their experiences (van Manen, Higgins and van der Riet, 2016).

The interviews can differ in how structured they are. It depends on several factors, including the level of pre-existing knowledge about the topic. Interviews, both telephone and face-to-face, allow the asking of follow-up questions. For example, an open-ended questionnaire would not be possible in other forms of data collection (Gelling, 2014). Semi-structured interview guides

contain an outline of topics (Stuckey, 2013). However, the structure is not rigid; participants' responses can guide the interview, and individual interviews can be in-depth. It is sometimes considered an ideal data collection method in qualitative studies (Adhabi and Anozie, 2017).

This data collection method fits in with the aim and philosophical standpoint of the enquiry. Interviews were used in order to explore lived experiences of thyroid cancer. In-depth interviews are an excellent tool for encouraging personal narratives. Although the researcher wanted to allow scope for respondents to define what was important to them, the researcher wanted to ensure that some key topics were covered with everyone, for example their experience of diagnosis and treatment. Hence, a semi-structured interview was used.

### **Interview guide**

The interview schedule was developed in order to make sure that all aspects of interest were covered. As the researcher is interested in holistic experience, the topic guide covered all parts of life and the cancer experience, including diagnosis, treatment, NHS care, friends and family, physical and mental impact, finances, work, daily life and activities. However, the researcher wanted the guide to be very open as the goal was to discuss important issues for participants. Therefore, although there was a core set of topics, the length of time spent talking about topic was determined by the respondent, which encouraged participants to talk about the factors that were most important to them.

The interview guide was developed and tried on one thyroid cancer survivor. It was then adjusted following that interview. The more interviews were completed, the more the researcher understood which questions could be asked first. Thus, the interview guide was not piloted but developed as the research progressed. Pilots in qualitative studies are not necessary but can be advantageous (Harding, 2019). The interview guide and all other recruitment documents can be found in the attachment section (appendix 9 on page 236).

### **Face-to-face and telephone interviews**

Both techniques have challenges and advantages. Face-to-face interviews allow for a full range of communication methods, including non-verbal communication (Harding, 2019) and are often the preferred method in qualitative research (Adhabi and Anozie, 2017). However, telephone interviews can be more convenient for both researcher and participants. In addition, they can be very effective in generating quality data (Holloway and Galvin, 2017). The challenges include the lack of non-verbal communication. The conversation may be more formal, brief or task-

oriented (Harding, 2019). Moreover, the relationship between participant and researcher is not as involved (Holloway and Galvin, 2017). Nonetheless, it is an excellent method when face-to-face interviewing is impossible (Holloway and Galvin, 2017).

This study used both face-to-face and telephone interviews. The initial plan was to conduct only face-to-face interviews with participants recruited from a local cancer care centre to gain from the advantages of face-to-face interactions. However, as the study evolved due to changing circumstances, including the initial slow progress of recruitment and the global COVID-19 pandemic, amendments were made to make telephone interviewing possible. The researcher observed that the telephone interviews were shorter, but the conversation was more direct and focused. During face-to-face conversations, there were many digressions made by participants. However, this could be because face-to-face interviews were at the start of recruitment, and the researcher's skills in directing focused interviews improved as the research progressed. Although telephone interviews were shorter, the researcher ensured that respondents discussed all the issues that were important to them by asking at the end of the interview whether they felt that they had discussed everything that was of importance to their own experience

Building a rapport was more challenging, as described later in this chapter. However, overall, the data quality from telephone interviews was also high. The adjustment was necessary for the researcher to conduct recruitment and complete the study promptly.

### **3.4 Study participants**

#### **Eligibility criteria**

The study population included adults (over 18) with a preferably recent diagnosis of well-differentiated thyroid carcinoma (papillary, follicular and medullary). Patients that were not eligible were those diagnosed with terminal thyroid cancer with a short life span prognosis, a different type of terminal cancer or Anaplastic Thyroid Carcinoma. It is because life expectancy is short. Thus the experience of patients will be significantly different. Moreover, the research sought to concentrate on thyroid cancer as an episode in life and eventually a part of life and its effects on lived experience.

#### **Inclusion criteria**

#### **Prospective participants**

1. Adults (over 18).
2. Patients diagnosed with papillary, follicular or medullary thyroid cancer within eight weeks of diagnosis (**or more than eight weeks if treatment has not yet started**).
3. Able to give informed consent.

### **Retrospective participants**

1. Adults (over 18).
2. Patients with a diagnosis of papillary, follicular, or medullary thyroid cancer within five years of diagnosis.
3. Able to give informed consent.

### **Exclusion criteria for both prospective and retrospective participants**

1. Diagnosis of anaplastic thyroid cancer.
2. Diagnosis of terminal thyroid cancer with short life span prediction.
3. Co-diagnosis of different than thyroid terminal cancer.

## **3.5 Sampling**

### **Sample size and sampling technique**

The researcher planned to recruit at least 12 patients and set a limit of a maximum of 25 participants. The maximum number of patients were successfully recruited. It is a relatively large sample for a phenomenological study. The decision about the sample size was made before the start of the research as it was a requirement of the NHS Ethics Committee and hosting NHS Trust to have a specified number of participants. The decision was made taking under consideration the scope of the study, the study's design, the project's length and the length of the PhD programme.

The initial plan of sampling can be seen below:

Sampling: Purposeful Sample of maximum variation (Purposeful, maximum variation sampling) adults diagnosed with thyroid carcinoma (papillary, Follicular, Medullary). It is an optimal sample; in practice this may not be easy to achieve as some pathways are more common than others.

- 4 Participants with Treatment option 1 (Partial thyroidectomy)
- 4 Participants with Treatment option 2 (Total thyroidectomy)

- 4 Participants with Treatment option 3 (Total thyroidectomy and RAI)
- 4 Participants with Treatment option 4 (Total Thyroidectomy, Neck dissection and RAI)
- 4 Participants with Treatment option 5 (Medullary cancer, surgery and chemotherapy)
- 4 Participants 1-5 years post-diagnosis.

The researcher wanted at least 25% of participants to be working parents to explore added pressure of cancer diagnosis of people juggling family and work commitments.

The purposeful sample is a sample where the researcher chooses which participants would contribute to the study in the best way (Polit and Beck, 2022).

However, difficulty recruiting meant that all consecutive eligible participants were accepted for the study, disregarding initial plans. It was a planned, alternative recruitment strategy. Thus, the sampling method was mainly a self-referred quote sample. The BTCT placed an advert on their Facebook and Twitter accounts. Within a few days, the remaining 22 participants were recruited. It was efficient but not free of bias. The discussion of the effect of the sampling method on the study is in the Study Limitations section on page 183. The final sample characteristic can be found on page 94.

### **Prospective and retrospective interviews**

Due to the challenges mentioned above, some participants were recruited prospectively and some retrospectively. Initially, the researcher aimed to recruit prospective participants and use face-to-face interviews only. However, due to slow recruitment and the global pandemic, the researcher decided to open the recruitment criteria to include patients whose treatment was completed and, therefore, would be interviewed retrospectively about their experience. This possibility was already considered and approved in the initial ethics application (the Northumbria University Ethics Committee and the NHS Ethics Committee). However, the change to include telephone interviews required amendment from both ethics committees. Nevertheless, it was promptly granted, and recruitment could continue.

The researcher would have preferred the study to recruit prospectively due to the above benefits. However, in this circumstance, it was not possible. The researcher is sure, though, that the quality of data from retrospective interviews was still of high quality and allowed the researcher to fulfil the study aim and its objectives. In addition, prospective participants enabled the researcher to get a ‘real time’ view of their lived experiences, although retrospective

participants seemed to have an apparent recollection of experiences at different stages of the process.

### **Prospective interviews**

The study had two elements, one prospective and one retrospective. In prospective studies, data is collected at baseline and then in subsequent follow-ups/other points in time. It can provide more substantial results than retrospective interviews as they avoid memory bias (Polit and Beck, 2004). The prospective enquiry follows people in real-time, exploring changes and experiences (Neale, 2018). The main risk of prospective research is participant retention. The risk of a participant dropping out of the study is higher than in single-contact studies. The quality of the relationship between researcher and participant and the length between contacts and their quality is vital. Consent needs to be sought at each contact (Treanor, Patrick and Wenham, 2021). Challenges may involve participants feeling disempowered or without control in a situation where long-term illness is involved. Health can also be unpredictable, impacting retention (Carduff, Murray and Kendall, 2015). However, despite the challenges, this research methodology can be invaluable.

In the prospective aspect of this study, the researcher followed patients through their journey through treatment and recovery up to ten months from diagnosis. All six prospective participants were recruited between 11/2019 and 07/2020. Initially, seven participants were recruited, but one did not respond to the invitation for a second interview and therefore was interviewed only once. Four participants had all three interviews, and two participants had two interviews. One missed the middle interview due to work pressures but sent an email update and volunteered for a third interview. The other participant had their first two interviews and did not respond to the invitation to participate in a third interview. Retention is a common problem in prospective studies, as discussed earlier in the chapter.

All prospective participants were recruited within the first two months of their diagnosis, which falls within the inclusion criteria. However, some participants received their diagnosis after their surgery. Hence at the point of the first interview, some participants had their surgery, or their first surgery was already behind them. The second interview was between two and four months after the first one. The third interview happened between two and a half and four and a half months after the second, five and eight months from the first interview, and six and ten months from diagnosis. Hence all prospective patients were followed up up to a maximum of ten months from their initial diagnosis.

## **Retrospective**

In retrospective studies, the data is collected at one point in time but regarding events or experiences from the past (Neale, 2018). Recalling experiences and feelings from the past may not be very accurate (Diener, Suh and Oishi, 1997). People's memories may be inaccurate. Only remember the most powerful feelings (Fredrickson and Kahneman, 1993).

In retrospective interviews with thyroid cancer survivors, the participants were asked to reflect on their experiences with thyroid cancer through different stages and their experiences and factors affecting it. All retrospective participants were recruited and interviewed in July and August 2020. All participants had their interviews within five years of diagnosis, which falls within inclusion criteria. Three participants had their diagnosis and started treatment in 2016, ten in 2017, three in 2018 and two in 2019. Thus, all retrospective participants were recruited between one and four years after their diagnosis.

## **Interview setting**

Face-to-face interviews happened in the participant's home or another suitable place of their choice, for example, a café or Northumbria University Library. The interview guide was used to make sure all the main topics were covered. Interviews were audio-recorded upon informed consent.

## **Diaries**

Paper journals were handed out to willing cancer patients (prospective participants) to record a reflective account of their treatment and experiences. Patients also had the option of using a journal application on their electronic device (mobile phone/tablet), web journal (online) or audio journals (YouTube, short videos on the phone). In addition, the researcher provided participants with a diary guide that can be viewed in appendix 11 on page 239. The structure of this guide was reasonably open. The guides for diaries can be very structured or very open in design. The unstructured form leaves much room for interpretation (Robson and McCartan, 2016).

The method of including diaries was a very promising idea. However, in practice, only a handful of participants attempted to write in their diaries. As a result, one of the participants provided an important addition to his interview, while two other participants reported essential facts about their cancer diagnosis and treatment, for example, the details of their appointments and their results. Only the records of one participant had any value for this particular study. In

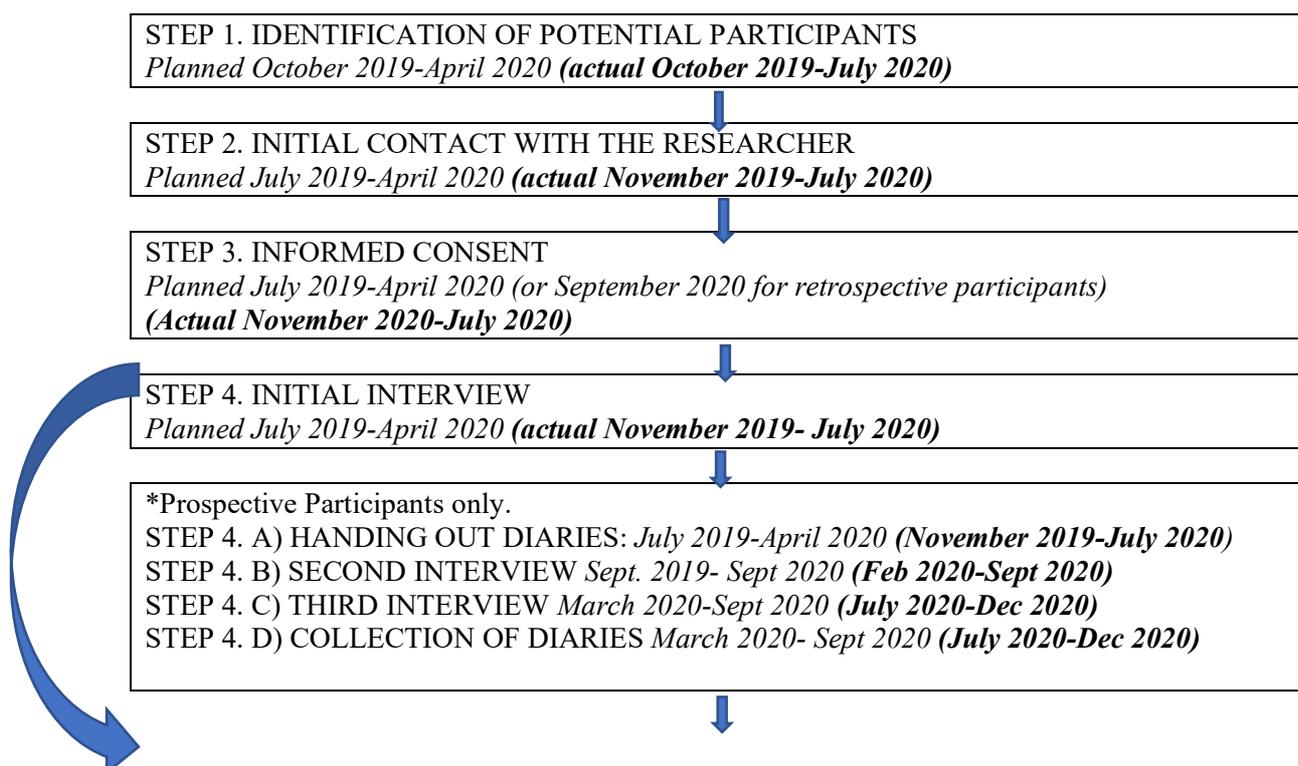
retrospect, if the researcher were to reattempt this data collection method, a higher number of patients would be approached, as the sample attrition (i.e., dropping out of the study) is much higher than with interviews. Also, this method would benefit people who already carry out reflective journaling throughout their treatment. It would provide more insight into their lived experience. Thus, in research using this collection method on this group of patients, a more focused sampling technique would be beneficial.

However, two participants were delighted with the introduction of journaling into their life. They found it highly beneficial in improving their wellbeing and would continue to do so even after the study was completed. This alone makes attempting this method worthwhile for the researcher.

Due to high attrition, it is recommended that this method is used in combination with another method, as in this study. Similarly to Crosbie (2006), who used diaries as a data collection method to supplement face-to-face interviews, it was a significant challenge to attract a sufficient number of participants to that part of the study. It is important to emphasise that diaries cannot be used in retrospective studies, so the limited number of prospective respondents limited the capacity for diary keeping

### 3.6 Schedule of procedures

**Figure 3.1 Time frame of the study**



STEP 5. DATA ANALYSIS July 2019-March 2021 (*Actual December 2020-July 2021*)

STEP 6. WRITING UP October 2020-October 2021 (*Actual July 2021-September 2021*)  
Some chapters were written in the year 2019 and 2020

STEP 7. DISSEMINATION *March 2021 onwards (Actual October 2021 onwards)*

**Table 3.2 Prospective and retrospective number of patients**

<i>NHS Prospective Participants</i>	3 (2 participants had 3 interviews, 1 participant had 2 interviews)
<i>NHS Retrospective Participants</i>	0
<i>Non-NHS Prospective Participants</i>	5 (1 participant had only 1 interview, 2 participants had 2 interviews, and 1 participant had all 3 interviews).
<i>Non-NHS Retrospective Participants</i>	17 missed steps 4A-4D as seen with a blue arrow on the left.

### **NHS Prospective participants (NHS01, NHS02, NHS03)**

1. Identification of potential participants. The thyroid Cancer Clinical Nurse Specialist introduced patients to the study by providing them with a Potential Participant's Information Pack that included a study leaflet, PIS and consent to contact in a pre-paid envelope. It happened in one of their standard care appointments.

2. First contact with the researcher. Potential participants interested in the study either contacted the researcher directly or signed and sent the consent to contact to the researcher. During the first telephone or email conversation, potential participants were able to ask questions and gain more detailed information about the study. Next, willing potential participants were invited for an initial face-to-face or telephone appointment. Pre-screening questions included:

- Clinical information: diagnosis and treatment pathway.
- Personal information: marital status, kids, employment situation.

3. Initial appointment. At the initial meeting or telephone consultation, participants could ask any questions they may have had. First, detailed descriptions of the study were provided. Next, the researcher went through the consent form, explaining the meaning of each statement. When the informed consent was signed, the patients were asked a few demographic and social questions and their diagnosis and treatment pathway. Then the researcher completed the interviews according to the attached guide (appendix 9 on page 236).

4. Handing out Diaries. During this first meeting, patients who were interested and consented to complete a diary were handed a paper diary with printed instructions on the first page.

The date and time of the next appointment were discussed.

5. Confirm diagnosis and treatment with health care professionals. After the initial interview, the researcher confirmed the diagnosis and treatment pathway by asking a health care provider (Thyroid Cancer CSN) to fill in the medical information request form. That was done for three NHS-sourced participants NHS01, NHS02 and NHS03.

6. Second Interview. The researcher contacted the participant, or the visit was booked at the previous contact. The researcher conducted a follow-up interview according to the follow-up interview guide.

If this was a final appointment, patients were asked to hand in the diary to the researcher.

7. Third Interview. The researcher contacted the participant, or the visit was booked at the previous contact. The researcher conducted the third interview according to the follow-up interview guide.

8. Collecting Diaries. Patients will be asked to hand in the diary to the researcher.

#### **Non-NHS Prospective participants (TC01, TC02, TC03, TC05, TC17)**

1. Identification of potential participants. All non-NHS patients responded to an advert posted by the BTCT via their Facebook and Twitter accounts.

2. First contact with the researcher. Potential participants interested in the study contacted the researcher directly. During the first telephone or email conversation, potential participants were able to ask questions and gain more detailed information about the study. Willing potential participants were given a Consent Form and PIS. They were also invited for an initial telephone appointment. Pre-screening questions included:

- Clinical information: diagnosis and treatment pathway.

- Personal information: marital status, kids, employment situation.

3. Initial appointment. At the initial telephone consultation, participants could ask any questions they may have. A detailed description of the study was provided. The researcher went through the consent form explaining the meaning of each statement. Then the researcher completed the interviews according to the attached guide.

4. Handing out Diaries. After this first meeting, patients who were interested and consented to complete a diary were posted a paper diary with printed instructions on the first page.

The date and time of the next appointment were discussed.

6. Second Interview. The researcher contacted the participant, or the visit was booked at the previous contact. The researcher conducted a follow-up interview according to the follow-up interview guide.

If this was a final appointment, patients were asked to hand in the diary to the researcher.

7. Third Interview. The researcher contacted the participant, or the visit was booked at the previous contact. The researcher conducted the third interview according to the follow-up interview guide.

8. Collecting Diaries. Patients were asked to send back the diary to the researcher.

### **Non-NHS Retrospective part of the study (TC04, TC06, TC07, TC08, TC09, TC10, TC11, TC12, TC13, TC14, TC15, TC16, TC18, TC19, TC20, TC21, TC22)**

1. Identification of potential participants. All non-NHS patients responded to an advert posted by the BTCT via their Facebook and Twitter accounts.

2. First contact with the researcher. Potential participants interested in the study were either contacted or contacted the researcher directly. During the first telephone or email conversation, potential participants were able to ask questions and gain more detailed information about the study. Willing potential participants were invited for an initial appointment. Pre-screening questions included:

- Clinical information: diagnosis and treatment pathway.

- Personal information: marital status, kids, employment situation.

The consent form and PIS were emailed to potential participants.

3. Initial appointment. At the initial meeting or telephone consultation, participants were able to ask any questions they may have. Detailed descriptions of the study were provided. Next, the researcher went through the consent form explaining the meaning of each statement. When the informed consent was signed, participants were asked a few demographic and social questions, and their diagnosis and treatment pathway. Then the researcher proceeded with the interview according to the attached guide.

### **Study setting**

It was initially a single-centre study. The site of recruitment within the NHS was a local centre of treatment of the disease in question (Northern Centre for Cancer Care, Freeman Hospital, Newcastle Hospitals NHS Foundation Trust). The Cancer Centre is located in the city of

Newcastle upon Tyne. It is the largest centre in North of England as a part of one of the largest NHS Trusts in the UK. The setting provided initial access to the participants. Initially, the original plan was to recruit all participants from this site. However, recruitment was opened to participants outside of the hosting trust due to difficulty recruiting. This did not impact the quality of data obtained and allowed for the inclusion of people treated in different UK-based centres. In addition, this allowed for a wider variety of experiences due to differences in management and care between centres in the country.

### **3.7 Ethical considerations**

This was a non-therapeutic, non-intervention study. It was high risk because some participants were recruited via the NHS. The participants in this study may be considered vulnerable as they had pretty recently received a cancer diagnosis. The risks included disclosing safeguarding information, distress, time-consuming and tiring interviews and talking about sensitive issues with a stranger. The benefits of participation included the opportunity to participate in a research study, the opportunity to express their emotions and explore their experiences, the opportunity to have their experiences validated, and the opportunity to help others potentially.

#### **3.7.1 Ethical principles**

It was important for the researcher to fulfil all the ethical and moral requirements of a modern healthcare study. Principles of biomedical ethics (Beauchamp and Childress, 2009) include respect for the autonomy of participants, the rule of nonmaleficence (not harm), the rule of beneficence (benefit participants if possible), and the rule of justice (provide truthful information and have good intentions).

Stanley and Wise (2010) provided five principles for researchers to follow in order to ensure the integrity of the research:

1. Gain informed consent (see details on page 86).
2. Respect the confidentiality and anonymity of research respondents (see page 92 for more information).
3. To ensure voluntary participation in the study.

Participants recruited from the NHS were given a potential participant information pack, and after reading the PIS, they decided whether to contact the researcher directly or to send a consent to contact. The researcher, acting as a CI for the study, chose the Local Collaborator as they are very experienced in recruiting patients to NHS studies and are familiar with GCP

(Good Clinical Practice) in research, where the voluntary aspect of taking part in research is pivotal.

Participants recruited with support from BTCT could self-refer and decided to contact the researcher to participate in the study. All participants were aware of the freedom to terminate their participation without stating the cause and without their care being affected.

4. To avoid harm to study participants.

See assessment and management of risks below.

5. To show that the research is independent and impartial.

Although BTCT part-funded the PhD and was involved in the research design and recruitment, they took no part in the collection or analysis of the data, and comments that were critical of them were given equal weight to comments that praised them.

The researcher followed the above rules and principles throughout the study process.

### **3.7.2 Assessment and management of risk**

#### **Interviews**

Interviews are time-consuming and may be tiring. Participants have to allocate up to 2 hours each time. In addition, they may have to adapt their plans for the day, which may be inconvenient. To minimise this, participants were asked about the best place, time and date for the meeting. Telephone interviews were also used. Participants were reassured that they could stop the interview or cancel or rebook it at their convenience. The interview could be completed in two parts if the participant preferred shorter interviews.

Participants may be uncomfortable inviting strangers into their homes and feel pressured to participate if the researcher has travelled to their location. To minimise this, participants were given the option to have the meeting at their home, the Freeman Hospital, Northumbria University or any convenient location for them.

Participants may become upset or distressed when talking about their lives and cancer. It happened a few times. The researcher is a nurse with many years of clinical experience and additional counselling training. The researcher provided support and reassurance within their competencies and professional boundaries. Moreover, a leaflet with information explaining

where participants could access extra support was provided. See the information leaflet in appendix 13 on page 241. Participants were reassured that they could stop the interview, withdraw from the study or avoid upsetting topics if they wished. Moreover, participants were reassured that they did not have to say anything they were uncomfortable with.

## **Diaries**

Participants may feel obliged to complete diaries even though they do not want to. The researcher emphasised that it is voluntary. Diaries are time-consuming and require self-reflection that can be painful or distressing. The diaries were not compulsory, and participants could still participate in interviews and not in keeping diaries.

### **3.7.3 Building rapport**

Health care professionals possess many communication skills derived from their clinical practice that may be very practical in conducting research in healthcare settings (Holloway and Galvin, 2017). In addition, the researcher who conducted this study supports the belief that the relationship between researcher and participant is based on respect, trust and equality as human beings (Holloway and Galvin, 2017).

The researcher is a practising nurse with over seven years of clinical experience. Communication is a big part of being a nurse, and the researcher felt confident that the skills allowed the researcher to communicate with participants in a very appropriate, sensitive and considerate matter. The researcher had a friendly but professional attitude and ensured that participants felt comfortable before any more sensitive questions were asked. Initially, the conversation involved going through the consent form or reaffirming consent previously signed.

### **3.7.4 Informed consent**

Informed consent is a vital part of a research project according to GCP (Good Clinical Practice) training that the researcher obtained when working for NIHR. Participants should receive a written consent form and a written participant information sheet. Information should be given to participants, and appropriate time should be given for careful consideration. All consequences of taking part in the project should be explained to participants (Harding, 2019). Informed consent is ongoing (Holloway and Galvin, 2017), and all benefits and possible risks should be clearly explained. The patient information sheet ensured that adequate information was given to study participants. They were also encouraged to ask any questions.

### **NHS participants**

At a prospective patient identification point (with the Thyroid Cancer Specialist Nurse), patients were given a Patient Information Sheet (PIS) or consent to contact. If patients decided to give consent to contact, the researcher contacted them and sent a PIS to their home address after their verbal consent. The consent was sought after a minimum of 24 hours from when the PIS was given to give potential participants time to consider their participation. There was an opportunity to ask questions and change their mind about participating in the study at any time.

At the initial appointment, the capacity of the potential participant was assessed. The discussion covered all points of the consent form as well as the description and rationale of the study. All questions asked were answered. All risks and benefits of participation were disclosed. The voluntary nature of participation was also emphasised.

### **Non-NHS participants**

Non-NHS participants were emailed a consent form and PIS at the initial conversation. The appointment for the first interview was booked for a minimum of 24 hours following the first conversation. Thus, prospective participants had the opportunity to consider their study participation carefully.

At the initial appointment, the capacity of the potential participant was assessed. The discussion covered all points of the consent form as well as the description and rationale of the study. All questions were answered. All risks and benefits of participation were disclosed. The voluntary nature of participation was also emphasised.

### **3.7.5 Research ethic approvals**

#### **University ethics**

The Northumbria University Research Ethics Committee approved the study (reference number 13824).

## **NHS ethics and Trust R&D approval**

NHS ethical approval was required for this study. Ethical approval was granted by the Newcastle and North Tyneside 1 Research Ethics Committee (ref: 19-NE-0175). In addition, Newcastle upon Tyne Hospitals NHS Foundation Trust approval was also sought and granted (study number 9055), and Caldicott approval was also given from the Trust.

## **3.8 Data analysis process**

### **3.8.1 Qualitative data analysis**

Qualitative data analysis is making sense of a large amount of data. It is generating meaning, exploring, and understanding the phenomenon in question. Qualitative data analysis has many approaches and methods. It is also more flexible when compared to more rigorous and systematic analysis in quantitative research (Polit and Beck, 2022). There is a wide range of possible approaches. For example, researchers can use discourse, thematic, comparative, and content analysis (Harding, 2019). The decision about which method should be used depends on the study's theoretical framework (Panke, 2018). Researchers can also use more manual approaches or coding software like NVivo and CAQDAS (Harding, 2019).

The researcher chose a method of descriptive analysis that has been described by Giorgi (2009). There are three methods of descriptive analysis that the researcher often uses. These are Giorgi (2009), Colaizzi (1978) and van Kaam (1966). There are also many methods in interpretative phenomenology. The Giorgi method was chosen for this study because it is a step-by-step method. It was developed by a psychologist and used to describe the phenomenon of lived experience. It involves a detailed examination of the participant's lifeworld. It explores the personal experience and is concerned with an individual's perception or account of an object or an event, as opposed to an attempt to produce an objective statement of the object or event itself. Giorgi (2009, pp. 5) describes the method as 'the study of a particular realm, the study of the experiential world of an individual. It can also be used from a discipline perspective, for example, in nursing (Giorgi, 2009).

### **3.8.2 Giorgi's method of data analysis**

The researcher used Giorgi's method as a basis for data analysis. The method has four steps shown below:

1. Read the entire transcription to get an overall sense of the whole

The researcher read entire transcripts

2. Extract meaningful units from participant's descriptions

The researcher used a computer program, NVivo, to code and theme qualitative data because it makes data analysis faster and more flexible (Bazeley, 2013). Meaningful units were extracted.

3. Describe the phenomenon more directly

The researcher gathered all units in groups and described the phenomena in each category. The researcher used imaginative variation to make that decision (page 90). All nodes were categorised into four major categories: organisational, personal, relational and communal. All other nodes were categorised into emerging themes under those four categories.

4. Synthesise all transformed meaningful units into a 'consistent statement.'

The researcher synthesised meaningful units and worked on statements within themes, containing the essential structure of aspects of the phenomena. Out of repeated units, some were chosen to illustrate the topic with a quote. Any new meaningful units coming from the data were either added to the synthesis or discarded repeated (Polit and Beck, 2004; Giorgi, 2009).

### **Natural attitude/reflexivity**

The natural attitude is an attempt not to allow presumptions, previous research experience and deduction to interfere with the data collection. However, it is not entirely possible as people naturally use their experiences and thoughts to bracket everything around them and better understand them (LeVasseur, 2003). Thus, the researchers may have limited possibilities for using bracketing. All the insights about the phenomenon in question come from what is given to the researcher (Giorgi, 2009). The natural attitude is similar to the concept of reflexivity. Having a reflexive attitude and questioning one's pre-understanding refers to the qualitative phenomenological enquiry interview stage. It uses a critique of the researcher's prior knowledge, and cultural influence and reflections put them aside to assist phenomenological

reduction (Koch and Harrington, 1998). For example, the researcher was aware from the literature that people without partners often found the cancer treatment experience particularly isolating. However, great care was taken to ensure that there were no additional questions about loneliness asked of single people, but all respondents were allowed to discuss this issue at length if it was important to them.

### **Imaginative variation**

Imaginative variation is an intentional mental effort to alter an aspect of a participant’s experience by either reducing it or adding to the ‘proposed transformation’ (Mueller and Spiegelberg, 1962). The effort aims to check whether part of the description can be included in the phenomenon's essence not (Hultgren, 1944). Imaginative variation was used when deciding which quotes best portray the described phenomenon. For example, when discussing how participants found out that they had thyroid cancer, the researcher included one account of a patient's conversation with their family. In the quote, the patient said to his sister: ‘Oh yes, I have got this big bump’. Here the description of the conversation is very much part of the essence of the phenomenon because it demonstrates the lack of concern that the patient felt prior to the cancer diagnosis.

### **3.9 Ensuring trustworthiness**

The table below demonstrates how the approach ensured that the characteristic of trustworthy qualitative analysis, as defined by Holloway and Galvin (2017), were evident in this study.

**Table 3.3 Trustworthiness in qualitative research ensures the soundness of data** (Holloway and Galvin, 2017)

<p><b>Dependability</b></p> <p>Consistent and accurate findings (Guba and Lincoln, 1989)</p>	<p>-The researcher used rigorous methodology and methods and described the processes</p> <p>-The researcher received extensive training when working as an NHS Research Nurse and a PhD student.</p>
<p><b>Credibility:</b></p> <p>Meaningfulness of the findings and presentation of findings (Holloway and Galvin, 2017)</p> <p>Assuring confidence in the research findings (Gelling, 2015)</p>	<p>-The researcher shared some transcripts with their supervisor to ensure similar themes were identified.</p> <p>-Rich descriptions with quotations are provided.</p>
<p><b>Transferability:</b></p>	

Usefulness and relevance of findings. The soundness of findings. Their clarity and originality (Holloway and Galvin, 2017).  Transferability to other settings (Polit and Beck, 2003)	-The researcher described the participants, setting, and methodology so that the reader could assess the extent of transferability.
<b>Confirmability</b>  The research findings are objective and not a result of the researcher's subjective biases (Holloway and Galvin, 2017)	The researcher used reflexivity extensively throughout the research process. As a result, the researcher was aware of previous misconceptions about the disease and previous experiences related to the condition.

### 3.10 Project management and data protection

#### Amendments

All amendments were dealt with according to HRA guidance and Northumbria University guidelines. Substantial amendments were dealt with by submitting a valid notice of the amendment to the REC for consideration. The R&D department of the NUTH was also informed by mail. The responsibility for managing the study, including amendments, lay with the researcher, Alicja Rogusz (then Alicja Yilmaz). The history of amendments and all versions of the study protocol and documents will be held in a study master file. The numbering of protocols will reveal the protocol's current version, for example, initial version 1.0, then 2.0. The history of amendments is provided in the appendix of the protocol (appendix 3 on page 204).

#### Patient & public involvement

The researcher sought patient and public involvement early in the design process of the study.

- PhD students at Northumbria University PGR seminar
- Thyroid Cancer Medical Clinicians from NUTH (Newcastle Hospitals NHS Foundation Trust)
- Thyroid Cancer Nurse Specialist from NUTH
- The staff of Butterfly Thyroid Cancer Trust
- Two patients with thyroid cancer, one current and one survivor of thyroid cancer

- Research Nurse from NIHR CRN North East and North Cumbria.

The researcher asked questions regarding the readability, volubility and reasonability of the study design and documents like the PIS (appendix 6, page 229) and consent form (appendix 7, page 233).

### **Protocol compliance**

Protocol breaches and deviations would be reported to the academic supervisor and, if necessary, to the R&D department of the NUTH. However, no breaches or deviations of the protocol were reported.

### **Data protection and patient confidentiality**

Patient confidentiality and data protection were safeguarded and managed following rules in GCP and the requirements of the Data Protection Act 2018 and the General Data Protection Regulations (GDPR). The identifiable patient data were securely stored in a secured U-drive (Northumbria University) in a password-protected word or excel file. In addition, participant confidentiality was maintained by anonymising data using a study participant's identification number NHS01, NHS02, NH03 for patients recruited via NHS Trust and TC01, TC02 for participants recruited via the BTCT charity.

Individual participants' medical information obtained as a result of this project was considered confidential and third parties prohibited access. The only person to have access to identifiable data and limited medical information was the researcher, Alicja Rogusz. Pseudorandomised data sets will be stored securely for seven years. Identifiable data will be stored for 12 months after the data analysis is completed. The researcher acted in the best interests of the participants and other people affected. The researcher acted according to their professional knowledge and the code of conduct of the nursing profession provided by the NMC (Nursing and Midwifery Council). As part of a consent form, participants consented to the possibility that confidentiality may be breached in a situation when there is a possibility of harm to the participant or others.

### **3.11 Chapter summary**

In this chapter, the researcher has described the study methods used and their justification. The study is a qualitative enquiry with a phenomenological study design. The researcher used

descriptive phenomenology and Giorgi's method of data analysis. A quota sampling technique was used. Due to the challenges in recruitment and the global pandemic, some changes to the research plan had to be made. Retrospective interviews were used to supplement the prospective interviews. Also, telephone interviews were used to supplement face-to-face interviews. Rich data were obtained and analysed. In the next chapter, the results of this study are presented.

## Chapter 4 Results- Factors affecting lived experience through the treatment and recovery

In this chapter, the results of the descriptive phenomenological analysis are presented.

### 4.1.1 Demographic and clinical information about participants in the study

**Table 4.1 Demographic information of the study participants.** The total number of participants was 25.

#### Age

Classification	Number of participants
18-30	4
30-50	11
50-65	9
Over 65	1

#### Gender

Female	21
Male	4

#### Marital status

Married	15
In a relationship	3
Single	3
Engaged	2
Divorced	2

#### Children

No children	8
Adult children	6
Young children	4
Teen children	4
Teen child	2
Pregnant	1

#### Living situation

Living with husband/partner and kids	11
Living with husband/wife	6
Living alone	4
Living with partner	3
Living with parents	1

#### Employment

Full-time	9
Retired	6
Self-employed	4
Part-time	3
Full-time student	2
Homemaker	1

**Table 4.2. Clinical information on study participants.**

Diagnosis

PTC (Papillary Thyroid Cancer)	15
FTC (Follicular Thyroid cancer)	5
Met PTC (Metastatic Papillary Thyroid cancer)	2
Met FTC (Metastatic Follicular Thyroid cancer)	1
PTC and Hurtle Cell Thyroid Cancer	1
PTC FTC and Hurtle	1

Treatment

PT (partial thyroidectomy) then 2 <sup>nd</sup> PT and RAI (Radioactive iodine treatment)	9
TT (total thyroidectomy) neck dissection and RAI	7
TT and RAI	3
TT	3
PT	2
PT then 2 <sup>nd</sup> PT	1

Medical History

None	14
Type 2DM	2
Depression	3
Other conditions past and present include back pain, kidney stones, Asperger's Syndrome, hypertension, gall bladder, hiatus hernia, coeliac disease, IBS, thrombosis, pulmonary embolism, epilepsy, migraines	11

As seen in the demographic and clinical information above, most participants were female, working age, employed, married, had children, and had no significant medical history. However, most participants were diagnosed with Papillary Thyroid cancer and had a total or partial thyroidectomy and RAI treatment.

## 4.2 Experience of Early stages of the Thyroid cancer journey from discovery to treatment

### 4.2.1 Before the diagnosis

Before the lived experience is discussed, some exciting information about participants' life before their diagnosis and the circumstances regarding the discovery of the cancer are presented. Most participants were healthy, active and had a healthy diet before diagnosis. Their lives were busy with work, family life and keeping fit. Being active and healthy were the most significant emerging themes when talking about life before being diagnosed with thyroid cancer.

(...) I don't drink, I haven't drunk alcohol for 14 years. I do regular exercise; I am a keen cyclist. My wife and I both have very healthy diets, fruit and veg, fresh and not much meat. So generally, a healthy lifestyle. NHS03int1

Sports enjoyed by participants prior to diagnosis include jogging, Tai Chi, running, cycling, marathons, gym classes, running, climbing, walking, Nordic walking, fitness and gym exercise. As for hobbies, participants enjoyed activities like cooking, travelling, reading, opera and theatre, socialising, and playing instruments. Apart from being active and healthy, a second theme emerged about having a routine but full and busy lifestyle. Also, several retired participants enjoyed their retired life and various activities. A few participants were in full-time education, one in the PhD program and one in the midwifery program.

As seen above, most participants had a normal, physically active, and busy lifestyle before their diagnosis.

### **Lump discovery**

Investigations into thyroid cancer usually start due to the patient finding a lump in their neck. Sometimes, the lump could be palpated; other times, it could be seen in the mirror:

One Sunday morning I looked in the mirror and there was a lump in my throat, which I had not been aware of at all, and it was the size of a small plum, so quite noticeable, and I couldn't quite believe that I hadn't noticed it before then, and knowing my mum's history I went straight to the GP, so the next day I was at the GP and the process began then (...). TC08

Alternatively, someone else pointed out when they have seen a shadow of a lump. For example, one participant had a doctor in the family that advised to get the newly discovered lump checked. Another one lost weight and then discovered a visible lump. The investigation into new physical symptoms can occasionally lead to the discovery of thyroid cancer. The symptoms include sore throat, clicking sensation in the throat, back pain, exhaustion, and vocal cord palsy. However, most of the time, any specific symptoms did not accompany the discovery of a lump that turned into thyroid cancer. It is important to note that according to the accounts, the first point of contact for most cases was a GP, and it was the GP that decided to initiate an investigation into thyroid cancer.

#### **4.2.2 Between discovery and diagnosis**

This section presents negative and positive experiences regarding the period between the discovery of the lump and the confirmed diagnosis.

### **Long wait to confirm the diagnosis**

Many people described this time in their lives as very long and distressing. All people experienced anxiety and uncertainty during investigations. At this stage, it is not usually confident if it is cancer or a typical benign nodule. Moreover, it does not know that it frustrates people and is a source of worry. One participant felt that thyroid cancer patients have low quality of life because of the waiting time that starts right at the beginning when they have to wait for confirmation of the suspected diagnosis. One participant knew they had cancer, but for some time, they did not know what type of cancer it was, which they found very distressing:

The first diagnosis after the MRI scan was a shock but so much so that I didn't really know what was happening, so it was just let's see what they say. The operation, because it was fairly traumatic, meant that I was then from the Wednesday until the Monday in a state of very much not knowing, which was quite unsettling. Because I didn't know what my future held. NHS01

Moreover, some participants only had their diagnosis confirmed after the histology results of their thyroid surgery. Hence the waiting for them was even longer. Although worried, some participants remained optimistic about the outcome. Mainly because most of the participants felt physically well during this stage of the experience. Most of them had not experienced any adverse physical symptoms as they usually come with the treatment stage. Only one participant described their pre-diagnosis state as tired and explained that it was due to overwork. Another reason for being optimistic was the knowledge that thyroid nodules are widespread and, most of the time, not cancerous. One participant said they did not worry if it is thyroid cancer, as it can be found in older people during section without causing any problem. Another participant felt that it is so unlikely that it is cancer that it is not worth worrying about.

As seen above, most participants experience a degree of worry and prolonged waiting in this journey stage. However, some participants remained optimistic.

### **Attitude of Health Care Professionals has an impact on patients' experience**

One of the most critical aspects of the experience of early stages of patients' cancer journey was the attitude of the healthcare staff. Sometimes, health care providers are so optimistic that they reassure patients that it will not be anything to worry about. For example, they were told that thyroid cancer nodules are widespread and, most of the time, not cancerous. Many participants talked about being reassured in the early stages. However, being reassured and then having been told that they have cancer made one participant feel vindicated:

A little vindicated because a lot of people said ‘Oh, this is nothing.’ The day they told me, I remember going in to see the surgeon, and they were like ‘We’ve got the results and it is not good news,’ and I just said, ‘It wouldn’t be, I told you it wouldn’t be. (...).  
TC06

For many participants, the friendliness and caring attitude of healthcare staff was critical in the early stages. Feeling reassured and supported was making the experience easier for them. However, a few participants had experienced impersonal interactions with healthcare providers during the investigation. Below there is an account of participants at their thyroid ultrasound appointment:

There was very little said during and after the scan and I remember thinking at the time that maybe she just wasn’t particularly talkative or was very busy. I do remember trying to say something while being scanned and was politely chastised and told to keep still and not to talk! Upon completion, I think all she said was that the Endocrinologist would be in touch in due course about the results. Upon leaving the room, I said to my wife that the lack of discussion, info or advice seemed a little odd and she said she thought the same too. (...) NHS03 diary

The testimonies of study participants suggest that although most staff they came across were supportive, friendly, and reassuring when met with cold and indifference, this experience stood out for them and stayed in the memory as part of the negative aspect of their thyroid cancer journey.

#### **4.2.3 Experience of receiving the diagnosis**

##### **4.2.3.1 Shock and distress of the diagnosis**

Most of the time, participants knew what the investigation could discover. They were told that, although unlikely, the investigation into thyroid nodules can result in a diagnosis of thyroid cancer. Some participants were not told about the possibility of cancer and found out after the initial surgery. However, even if they knew this was a possibility for most people, their first reaction to receiving a cancer diagnosis was shocking. They were not prepared to receive the diagnosis:

‘It does sort of knock the stuffing out of you. One minute you’re feeling perfectly okay and the next minute it’s as if someone has just handed you a poisoned chalice!’ NHS03int1

A couple of participants expected the news due to prior indications like the behaviour of healthcare staff during an investigation, the urgency of appointments or just intuition. However,

expecting the news or not, all participants found that receiving the diagnosis of cancer was very distressing:

(...) I was so upset by that time, I was crying and stuff, then we went into a separate room and sat with a nurse, she gave me like a Macmillan leaflet and signed all the paperwork for prescription, and things like that. We sort of just asked her a few questions, and stuff, and she gave us contact details, all that kind of thing. TC01

One of the predominant emotions at this time was fear of death. Although participants were reassured that their chances of cure were incredibly high, the first thing that came to their mind was the vision of dying of cancer. Especially as most participants were on average young and never faced with severe illness in the past. One participant referred to the diagnosis as a death sentence. Some also were worried about how their life will be affected and what their lives will look like after cancer. They were also worried about their families and friends. Sometimes, participants found it difficult to 'wrap their heads around it'. However, in most cases, the diagnosis was confirmed when the results from histology of the removed thyroid gland came back as thyroid cancer. It meant patients found out that they had cancer, but it had already been removed by surgery:

'So, it was difficult to realise in my head as I found out after the surgery that there was cancer, so I was cancer free but, in my head, I had cancer. It was difficult to sink in.' TC19

Sometimes, cancer diagnosis comes in during already a difficult time. One participant found out about thyroid cancer when heavily pregnant with twins. The participant wanted to concentrate on the pregnancy and birth of children and not cancer. Hence the topic of cancer was hardly spoken about. They did not tell anyone about the diagnosis. A cancer diagnosis brings a variety of emotions, including shock, distress, worry, fear and embarrassment. The news of thyroid cancer diagnosis disrupts people's busy lives and affects their lives for a long time.

#### **4.2.3.2 Lack of previous knowledge of thyroid cancer**

The shock and confusion may have also been intensified because most people had no to minimal previous knowledge of thyroid cancer. While most people know about other common forms of cancer, for example, breast cancer, they are unaware that you can get cancer in your thyroid:

'No, I've never, I 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, so yeah'. TC01

Moreover, association with the word cancer and previous experience can affect how people react to their diagnosis:

I was completely devastated about it. My stepdaughter's mum had endometrial cancer and now she has since died. I don't know how I would cope, there is too much cancer in their family, my mum died of cancer, my daughter was six then. How is she going to cope when I die, because I will die obviously just a very stressful time, it was just one thing on top of the other, absolutely devastated. TC14

Only people who knew someone with thyroid cancer had some previous understanding of the condition, but most study participants admitted to non to very minimal prior knowledge of the condition.

#### **4.2.3.3 Absence of family at diagnosis**

Surprisingly, quite a large number of patients were not told to bring any family members to the appointment on which they were told that they had cancer. In addition, some participants were not told to bring a family member to the appointment. Lack of support at diagnosis proved to be very distressing:

(...) I went to the meeting room, to the Dr, and I had no idea that it would be anything bad. My mam and dad weren't there, I did morning at work. And basically, the Dr said that they found two types of cancer. And I honestly wished that I could just walk out of that room and never come back to that room again. NHS02

Participants that did bring family with them to the appointment appreciated their presence:

'They told me it is cancer; it was important to have my family around me when I got this news really'. TC02

It is clear from participants' accounts that the presence of family is significant when receiving news of thyroid cancer. The lack of family at diagnosis made the experience of diagnosis more distressing.

#### **4.2.3.4 Attitude of health care professionals**

Most people were happy with the way their diagnosis provision was handled. They felt that they had received adequate support and information:

(...) The consultant was very good, I thought he handled it very well, he went, explained. (...). So, he sort of said you know, but then very quickly he sort of said that we know how to treat it, and there is a very good chance of curing it and stuff, so

although he gave me the bad news, he was very reassuring at the same time so, yeah. He handled it quite well (...). TC01

After their diagnosis was announced, supportive discussions with nurses were offered to most participants. At this point, most patients were given information packs and were informed about future treatment. However, this process did not always go smoothly. For example, one participant was told to wait for a nurse who would review all the necessary information. After waiting 45 min of waiting, the participant left and used google to learn information about the new condition. Another participant had a negative experience with the attitude of their medical team toward their condition:

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

Another participant did not feel included in decision-making regarding her condition. They felt that they were just abruptly told what the treatment would be without getting a change of marking choices or having input in any decision-making. That participant had an operation that they finally regretted. They have refused the RAI treatment. The participant stated that if they were supported more initially and given the option, they would not decide to get the surgery.

As seen, the attitude of health care professionals during early stages of the thyroid cancer journey is very impactful on people's experience.

### **4.3 Experience of treatment**

#### **4.3.1 Feeling about future treatment**

##### **Distressed waiting**

Several participants expressed that they found waiting for treatment both long and worrisome:

‘This is why one of the problems with wellbeing and thyroid cancer patients is so bad, it takes a long time between when they get diagnosis and when they receive the treatment.’ NHS02int1

However, not all participants felt that waiting was very long. On the contrary, some stated that everything happened very fast and efficient.

## **Fear of the surgery and consequences**

Fear of the upcoming surgery was common among participants in the study:

At that point I was very scared of the surgery, and the thought of it just terrified me. The thought of somebody cutting around my neck like that was very upsetting. I had a friend who had a similar operation, he had a neck dissection, he had this done, but yeah it was a very frightening time. TC10

The main reasons for fear of the surgery were going under general anaesthetic, never having experienced hospitalization before, being away from young children, complications from treatment, general implications for their health, painful recovery, side effects like feeling tired, hypothyroidism, hyperthyroidism, infection, and damage to vocal cords. In addition, two participants were involved in singing and were both extremely worried about the quality of their voices following the surgery on their thyroid. However, both were aware that the risk of that is small and found this knowledge reassuring.

## **Worrying about a scar**

Most participants did not express significant worry about future scars. However, for a small number of participants, this was a significant issue:

I was scared, they told me I would have an operation on my neck, and that I would have a scar on my neck, so that really frightened me, as a woman you are more conscious about your body, so I had to think ok now I will have a big scar on my body. TC11

Most participants did not worry about the future scar, including two male participants.

## **Well informed and reassured**

Most participants felt they were well informed about the risks of the surgery. They were reassured by their doctor, their expertise, their reputation, and the volume of surgeries they perform:

I was quite reassured to be honest. When I saw Dr (anonymised) and Dr (anonymised), two of the top ones. I know they are both respected in the field. Centre of Excellence. I knew I was safe in their hands. So, it was quite reassuring to know what the treatment plan was. NHS03

## **The positive feeling regarding treatment**

A high number of participants had various worries. However, some participants felt lucky about the treatment they would have to endure, taking it into perspective when comparing it to other cancers:

(...) I was quite..., I felt quite lucky, that it was all that I had to do, shall we say. (...) And I had friends and family who had it (cancer). I was quite relieved, that that is all what I am going to have. TC06

As seen above, some participants were experiencing distress while waiting for their treatment. Moreover, they were experiencing fear of both the surgery and the longer-term impact on their life and health. Also, worry about the scar significantly impacted some of the participants. However, some participants felt well prepared and reassured and had positive feelings regarding future treatment.

### **4.3.2 Positive Experience of thyroid surgery**

Participants had various experiences regarding surgery, both positive and negative. Although the quality of surgery was important to all participants, 18 participants expressed their satisfaction with the quality of their surgery and overall experience:

I had really positive experience of the operation, for me I came to a point that I was tired of being frightened, so the day of surgery, although I was very scared, I hadn't had any emotions left, I wasn't crying or anything, I just wanted to get it done (...). TC10

The physical aspect was one major factor that positively improved the way the surgery was perceived. As many people were worried about pain, being comfortable during and after the surgery made the experience more positive:

'(...) I have nothing to complain about, I was not in a lot of pain, drains were uncomfortable, and peeing in the bed pans was horrible. It was not designed for women to use like that.' TC09

### **Outstanding care**

Apart from physical factors, the second significant factor positively impacting the surgery experience was excellent care in the hospital. Their positive experience mainly relates to care provided by the hospital's care team:

It was amazing, I was in awe of the NHS before but after this and obviously after lockdown, they couldn't be more reassuring, very personal, I was lucky that the hospital I went to had a new treatment centre. Couldn't be more reassuring. (...) I can't fault my care at the hospital at all. TC15

Some ways of describing care by study participants included being superb, lovely, great, kind, excellent, brilliant, good guys, a top surgeon and attentive. Most participants felt they had excellent care, were informative and supportive, could ask for help at any point, and were treated with respect, dignity, care, and attention. One participant felt that the kindness of everyone in the hospital made this a positive experience. Another critical factor was the reaction to adverse symptoms. For example, one participant started experiencing symptoms and was quickly assisted:

They were superb, from arrival all the way through nursing care was amazing, the first night after the surgery during the night, I felt like my fingers were tingling, they immediately arranged for the doctor to take bloods, to check if it was a calcium problem which it wasn't, but everybody seem to be on the ball, and they knew what they were doing. TC08

The accounts above illustrate how important kind and professional care is in creating positive experiences for patients going through cancer treatment. The key to reassuring the participants was the kindness and friendliness of the staff, a good level of clinical, medical and nursing care, as well as confidence in the expertise of the team. Also, keeping patients as pain-free as possible makes the experiences more positive.

### **4.3.3 Negative experiences of surgery**

#### **Negative physical aspects of surgery**

All participants experienced various degrees of pain after the surgery.

In addition, a small number of participants experienced other ailments, for example, feeling unwell after general anaesthetic:

'I was very sick, when I woke up, just the whole, and I had to have a drain, just the whole thing, just pretty horrific'. TC03

These are common symptoms after general anaesthetic and were usually managed with adequate pain control and antiemetics (medication to stop feeling sick and vomiting).

## **Negative experiences of care**

There were reports of inadequate care, including the uncaring attitude of nurses. Slow response to buzzers was a frequent complaint, and inadequate pain medication.

When I woke up, I didn't feel very well, I was in a lot of pain, actually my experience of being in the hospital wasn't very good. And I was waiting very long for pain medication. I think sometimes I was waiting up to 2 hours for pain medication. I don't think that the level of care was up to standard, I appreciate NHS staff are stretched, but at a minimum you would expect a level of care. At night I was on my own, it is not that my family were there to comfort me. I was on my own and I was in pain and the stronger pain medication was paracetamol. Yes, they gave me paracetamol and ibuprofen. And because it was neck dissection it went all the way round my neck, that is where it was very painful and swollen. TC11

One participant felt she was being rushed. They felt like they were being rushed through the day of the surgery from one stage to the next, which they found very distressing. Other participants felt forgotten and left alone for an extended period of time. For one of the study participants, the experience of care in the hospital was traumatising:

When I came back after recovery I vaguely remember struggling to breathe and I had an oxygen mask on and then they realised that somebody forgot to plug that mask on. So, somebody plugged that in, and I could breathe again, so it was quite traumatizing, it was really horrible. TC13

Another person was left without access to the buzzer and was unable to call in case they needed someone:

(...) and she instead of putting my buzzer back to me, she put in on the wall, and I said I can't get up I can't reach it, and she said you've got everything you are going to need. TC04

This participant also overheard that he was blocking the bed due to '*bad water works*'. TC04. Their overall experience was very negative. This participant felt uncared for, neglected and disrespected.

## **Lack of advice about how to take levothyroxine**

Moreover, the lack of information also included a lack of information and understanding among health care professionals. Most people in the study were looked after in a general surgical ward and felt that the staff were not very knowledgeable regarding their condition and the care needed. For example, patients had little to no advice about taking levothyroxine, a new medication for them. Also, some nurses did not know that levothyroxine should be taken 30 minutes before food and without other medication, especially calcium. They were not told how to take it and only found out when they read the leaflet. Some patients had it given by nurses at

the wrong time, for example, with breakfast when it should be given before any food. Some participants expressed dissatisfaction with the information about the new lifelong treatment of levothyroxine was handled:

(...) After the second surgery, they told me ‘right you have to start thyroxine today’, and they just gave it to me I didn’t know how much I was taking, I didn’t know anything like that. The first one I was by myself, and I started to learn things by myself, you have to wait for like an hour after taking thyroxine to take any caffeine or food, I didn’t know that, no one told me that neither, so I found that out from the Butterfly page, and staff like that from other Facebook groups. TC03

For all study participants, embarking on a lifelong treatment with levothyroxine significantly changed their lives. Most of them had never taken any regular medications before.

### **Disturbing environment**

Some participants complained about the environment in the hospital. For example, a chaotic, rushed environment was distressing for a few participants. Another issue was with noise. After surgery, patients want to rest in a quiet environment, and busy hospital wards can be very noisy:

(...) I didn’t sleep well that night. The room is quite close to the road and you do hear the traffic. It was very windy that night and you could hear it against the window. Added to that, the door of my room kept rattling, so I just left it ajar, but the downside of this was you could hear noise from the nursing station, just a few meters down from the door. Yes, it is nice to have your own TV and shower/toilet, but to be honest, I’d have preferred to have stayed in the public ward, where you can have a bit chat with the other patients. NHS03

The above participant felt the single room was very noisy, but at the same time, they felt lonely and wanted some interaction with other patients. On the contrary, another participant found staying on a ward with multiple other patients quite distressing:

I don’t think I did, I feel bad saying it, because, obviously, with NHS, it is free, I am being looked after, on the ward that I was on to start with, it was a surgery ward, so everyone was different, so there were people with removed bowels, people who had had a hysterectomy, and I was the youngest on the ward by about 20 years. TC03

Although most participants in the study did not complain about the hospital environment, a few had negative comments about it that affected their experience of thyroid cancer surgery. To summarise, the negative experience of surgery is related to high levels of pain and discomfort, negative experiences of care, lack of adequate support and a disturbing environment.

#### **4.3.4 Experience of recovery from surgery**

Most of the participants were discharged home the following day from the surgery.

## **A positive experience of recovery**

Although most participants found the recovery challenging, a few had a positive experience their recovery:

‘(...) I can eat, I can talk, I can breathe, everything was great, ok.’ NHS01

Some participants expressed that they had recovered relatively quickly. Between a week and a couple of weeks, they felt good, especially as the time passed after the surgery. Some experienced ups and downs in their recovery process:

It probably takes you about a week to go back to your normal energy levels. I don't know whether it's just the after effect of the anaesthetics, or the fact that you have had a major operation. It takes the anaesthetic a while to wear off. I actually felt better on day one and two, than on days 3 to 6. I mean, after a week basically you are back to normal. just do what you normally do. It wasn't a big problem. NHS02int3

## **Negative experiences of recovery**

Recovery proved physically challenging for many participants who experienced symptoms, side effects and challenges after the surgery. Some general comments about recovery included challenging, difficult, not easy, and not grand. One participant's account of recovery indicates how difficult the experience may be for people that just had their surgery:

I found it very difficult. My mobility was reduced, I couldn't wash myself properly or wash my hair. But because I live with my partner it wasn't so bad as I wasn't on my own. But I just found it very lonely, I wasn't working, I took 10 weeks off sick, in total from diagnosis. I spent a lot of time at home on my own. I felt like a child as I couldn't do things. I had strict routine, with medication and physio exercises, so I had alarms going off all day - take this tablet, do this exercise. Quite intense, and again it was such a new experience as I never had any health issues. I was bored I didn't have anything to do apart from watching TV. I felt my life was on pause, I didn't get invited to anything.  
TC11

The most common complaints regarding the surgery were tiredness, pain, swelling, voice problems and swallowing discomfort.

## **Recovery physical symptoms**

The main physical complaints during recovery were tiredness, pain, voice issues, swelling and swallowing discomfort. Tiredness was among the most common ailments following the surgery:

And then, for the 2 to 3 weeks after the first operation I felt absolutely dreadful. Like really, really exhausted. I think I would be like; I would wake up in the morning and I would go to sleep in the afternoon for like a good few hour, and then go to bed early for the night. Before I had the surgery, I was like taking completely good care of myself. I was like, I had loads of energy. Whereas I don't feel like that now. NHS02

However, it is essential to note that most people who had only a partial thyroidectomy reported that their energy level went back to normal quickly after the surgery. Although, for many people, tiredness improves in time, tiredness is one of the symptoms that have the potential to linger for a long time. Many people reported pain in the early recovery period. Most of the time, the pain was in the neck and wound area. However, many participants expected to have some postoperative pain, and it quickly subsided. Patients usually get discharged with paracetamol and ibuprofen. No stronger medications should be needed following thyroid cancer surgery. However, the pain was more intense for participants that had neck dissection:

There were problems with pain relief afterwards, I had a couple of bad days when I couldn't manage the pain. I was taken off the morphine, because I think I was doing quite well and then the pain became much worse, so I had to go back on it. It made me feel sick, but then I came off it again and I was ok. I stayed in the hospital for 6 days. TC10

Participants who required neck dissection usually had staples on their wound and were in significantly more pain than participants with a small front incision. Although most participants reported no issues with their voice post-operatively, a few reported some minor issues, including the voice being husky, croaky or weak. One participant did sing before his operation. However, following the surgery, they expressed:

'My vocal cords felt anaesthetized. I could not make the sounds.' TC04

Although it improved, he never recovered the quality of his voice, which affected his singing performance. One participant still had serious voice problems when the study was conducted a few years following the surgery. Problems with the voice can be an issue long after recovery. Swelling in the wound area was a common complaint after the surgery. However, most of the time, swelling gradually decreased:

I didn't have the drain and I did have some swelling on the site of the surgery, fluid retention and he drained it, and it was fine, it was just once, I did have some swelling and I had an appointment, he palpated my neck and gave it a good squeeze and it disappeared, so it all healed up pretty well, you can hardly notice. TC08

However, one participant has permanent swelling following the surgery. A few participants complained about discomfort when swallowing. The biggest complaint regarding swallowing is a pulling sensation:

(...) it was really quite hard to swallow, I vaguely remember doing something strange to be able to swallow so I had to over exaggerate when swallowing to be able to do that. Pointwise I wasn't in a lot of pain, it was more uncomfortable. TC13

Some people had persistent symptoms even weeks after surgery. Nevertheless, it improved with time, even if it took a bit longer. Other less common complaints included constipation, hair loss, sleeping problems due to pain, reduced mobility, and numbness at the wound site.

### **Postoperative Complications**

A few participants experienced postoperative complications. The most common complication was an infection of the surgical wound and swelling that needed to be drained:

After the operation I had infection in the wound. And then second time around I ended up in the hospital as I ended up with cellulitis and was on the verge of sepsis. Since then, I've read that infection may be a common problem. And I was fine after my first surgery, energy wise but I was not prepared after the 2nd surgery that my levels would drop, weight loss would go on and I would be constantly tired all the time and until I started with a personal trainer, I just assumed that life that is just how it's going to be. TC16

One participant had calcium deficiency, even over six months after the surgery. Frequent visits to endocrinologists and blood tests helped lower the levels and remove the symptoms of tingling in fingers and tiredness. Another participant had a calcium fit and had to stay in hospital for two weeks following multiple calcium drips. Shoulder nerve damage was another complication. One participant is left with weakness in the shoulder, nerve pain, and sometimes spasms across the neck. The surgery left them with a permanent disability affecting their daily living, for example, making simple activities like washing hair challenging. Another participant in the study reported problems with high blood pressure. However, this participant had treatment with a drug called Lenvatinib, where high blood pressure is a common side effect. Hence, this would not be an issue for most patients with thyroid cancer. Furthermore, one of the participants experienced a severe panic attack on the night of discharge. The quote below describes the incident:

(...) I came home on a Friday, and they gave me the mobile number if I was worried about anything, to ring and speak with a nurse, and within 2 hours of me getting home, I don't know whether I was just anxious about, you know (...), but I got very anxious, I think it was a psychological thing, I thought that my throat was swelling, and I got myself really anxious and worked up. We rung the number and there was no answer, we tried five times, we couldn't get through to anyone, (...) I couldn't move, they were all tingly, but they were rigid as well, I've never had a sensation like that before, which made me panic even more, so my husband rung 999. As soon as the (paramedics) arrived, I calmed down, they were really good, they said look, everything is fine, your neck is not swollen, you have a good airway, your sats are 99%, your breathing is fine and you are getting plenty of oxygen, they stayed with me for about half an hour and

they were really good, they calmed me down, so that was horrible experience really.  
TC01int2

As seen above, there were several complications experienced by study participants. However, most of them were experienced by one person, apart from swelling and draining of the neck area, a more common complication experienced by a few study participants.

#### **4.3.5 Experience of a second surgery**

Almost half of the respondents had two surgeries. Most people knew what to expect and were not too worried. A positive experience after the first surgery was reassuring for some participants. At the same time, negative experiences at the first surgery made people more worried about the second one. They were worried that the experience would also be very negative. However, most participants had a positive experience with their second surgery:

And actually, the second surgery wasn't that bad. So, I think, I don't know, I think, because of the size of the lump, it was such a big lump, and they gave me so much anaesthetic, it made this surgery a traumatic experience. (...) I think the thyroid itself was a lot smaller, you know, there wasn't a large lump, so it was a much easier procedure for them to remove it. NHS02

Moreover, for one participant, it was worse in the psychological domain:

'Second time was worse, I was in a really, really bad state.' TC04

The second surgery proved to be a more effortless experience for most people. They knew what to expect and felt better prepared.

To summarise, the experience of the surgery stage of the treatment varies between participants. Most participants had a good surgery experience, felt relatively well and had outstanding medical and nursing care. Negative aspects of the experience were pain, especially when not well managed with pain killers, inadequate and uncaring attitude of staff in the hospital and complications. Also, a lack of adequate information regarding levothyroxine was evident. Moreover, some participants found the environment in the hospital to be too chaotic and noisy.

The experience of recovery was challenging for the majority of study participants. It was mainly physically challenging with symptoms like tiredness, pain, swelling, voice problems, and swallowing discomfort. Some participants had more significant complications like permanent swelling, nerve damage or long-term issues with calcium levels. Most participants, however, recover well from thyroid surgery. The second surgery was worrisome for some, while others felt prepared and knew what to expect. Overall, thyroid surgery is an important event that

affects the lives of people with thyroid cancer. It may come with physical and psychological symptoms, long-term symptoms and complications that can affect and disturb people's normal everyday lives.

#### **4.3.6 Experience of Radioactive Iodine Treatment**

In the study 18 out of 25 participants had RAI treatment.

##### **Anticipation and Feelings before RAI**

Although RAI is not a particularly invasive intervention, it proved to be a source of worry for some participants. Their main reasons for their anxiety were lack of familiarity and previous knowledge about the procedure:

(...) um, I suppose, I was slightly wary, because you always hear things about cancer treatment, I didn't know what radioactive iodine treatment was, I sort of expected my hair to fall out. I sort of went to it sort of overnight. I didn't worry about how I felt that it will make me better. TC16

Some participants were worried about toxicity and the side effects of the treatment:

And the thought of having radiation, to take this thing that you normally should completely avoid, is just a horrible thought. You know, what side effects it is going to have, long-term complaints, I know that they say it is very minimal, but there is a huge worry. And you know, for the last (age anonymised) of my life I thought that I was completely healthy. And, apart from the lump, I've always felt perfectly healthy. NHS02

The above participant decided not to have the procedure; against medical advice, they stated that there is insufficient evidence to suggest the need to have RAI as following surgery, there may not be any remaining tissue.

Other worries that people had regarding this treatment included the effectiveness of the treatment, toxicity of the radioactive iodine and possible side effects, leaving the children and potentially putting children at risk of toxicity, and a lengthy stay at the hospital. However, some people felt reassured with the information they were provided and felt good about their future treatment. Nevertheless, after learning about the procedure, few participants felt relieved about the treatment, its lack of invasion and its simplicity.

## **The positive experience of RAI**

In most cases, the anticipation of the treatment was worse than the experience. A few people expressed that RAI treatment felt very anticlimactic:

Staff were very good, and they said we know you are on your own here, but we are here if you need anything. And they kept sticking their heads round the door saying you ok? Even if they were doing it through the night. But I know they were just doing their job. The hospital I was at is very good, the food was good, the staff are good. I didn't feel any sickness or anything. I was quite surprised that I could go home so quickly.  
TC01int2

Factors that affected the positive experience were short stay, no invasive procedures, no side effects, being shown the isolation suite beforehand, having things to occupy them and avoid boredom during treatment, having another patient next door having the same treatment, being placed in a pleasant environment. Participants especially appreciated suits that BTCT renovated. Also, most participants were very pleased with their encounters with nuclear department practitioners. Participants described them as highly informative, kind, and a pleasure to interact.

## **The negative experience of RAI**

Factors that impacted the experience negatively include going to the hospital alone (during the COVID-19 pandemic), isolation, confinement, being bored, feeling forgotten, the suit being very small, being served bad hospital food, food being served very late or not at all. One participant was very distressed after the experience of RAI and needed charity support:

After RAI I was in a very bad state. I had counselling and it wasn't about cancer it was about all life. We are so lucky to have this charity, you get counselling or therapy I chose the counselling, and they do reflexology or other alternative treatment. TC04

## **Isolation and confinement**

Most participants felt some form of isolation during the procedure:

It was a horrible experience being shut in that room, with no contact with anyone, I had a telephone, you really did feel unwanted, unloved. I went on Wednesday till Friday. The second time was the same. The second time was nicer because the room was decorated. At the first time I think the prisoners have better rooms. First time round I had to phone them to bring me a jug of water, because they forgot about me. TC05

Another participant did not feel very well in a confined space. They felt claustrophobic, and everything in the room was covered in plastic. Also, this participant experienced a panic attack while in isolation and stated that the experience of RAI was far worse than surgery.

### **Physical symptoms during and after RAI**

While some people did not experience any symptoms related to RAI, symptoms commonly reported were taste alterations, sore saliva glands and tiredness. Taste alterations usually were experiences only temporarily. Some people experienced no taste alterations. Others were not sure.

I also noticed after RAI change in my taste, everything was bland, I didn't feel metallic taste like some people, just bland taste. Everything was tasting like nothing. Mainly sweet and salty, I couldn't taste anything. It makes you realise how much you enjoy the taste of things. It is strange. TC01int2

It is one of the most commonly experienced side effects among participants of this study. The pain ranged from mild ached to more significant and disturbing. Below there is an account of the participant who had the most severe case of saliva glands problems:

Also, the first day of tablet I was fine, but the second day my salivary glands were rock solid, but they said it is ok, it can happen, as soon as I had few glasses of water the pain subsided, but I had some swelling. (name of nurse) said that if there are any problems she will come up, she was very reassuring. When I get dehydrated, my saliva glands get very hard, and I have to massage them, and I've noticed that since then when I drink a lot it is easy for me to talk and my neck isn't constricted, but when I've had a busy day and been talking on the phone a lot, my neck feels really hard and tight. I never used to have this sensation before having it out. I had a high dose of RAI. They said it could last 6 months or so. But I kind of know when it can happen, and I drink more. TC15

Few people experienced tiredness following RAI. It lasted even up to a few weeks and usually subsided.

### **RAI - low iodine diet experience and issues**

Participants had mixed opinions about the diet, and some did not mind, while others found it difficult to get used to it and plan their meals:

To be honest I thought that I would feel bad after cutting out dairy and other things, but I actually felt much better, and I really wanted to stick to it, but I was bored at my mum's and that was it. But I know some people find it harder than others. Even the first days I had chicken and veg I just felt like I am on a normal diet. TC17int3

A low iodine diet was not a change that people were looking forward to. One participant was worried about her work-related functions and how she would manage during them. Another

participant did not understand why it was needed. People were also confused when they received the non-recommended foods during treatment in the hospital when they expected to have a low iodine diet.

As seen above, RAI treatment can be a positive experience for many participants. However, some participants thought it very challenging, especially concerning loneliness and isolation. Other issues identified by participants were feeling forgotten, issues with hospital food and boredom. In addition, while most people did not experience significant physical symptoms during or following treatment, some participants experienced pain in their saliva glands, tiredness, and temporary taste alterations.

## **4.4 Life after Treatment**

### **4.4.1 Long Term symptoms post-treatment**

Although all participants experienced short-term immediate symptoms to some extent, long-term side effects were experienced by some participants. Conversely, a small number of participants reported a lack of any long-term symptoms. Sometimes the symptoms may be minimal:

The physical bit, I think it because I am lucky physically, I am ok, I've got a bit of stiff shoulder, but that is not the end of the world, my neck is a bit puffy, but that is really, compared to, you'd rather have that than cancer, you know, I suppose you think, yeah that is fine. TC01int1

Most people have one or a few long-lasting symptoms related to their thyroid cancer treatment. The most common symptoms reported included fatigue and neck tightness. Other reported problems include voice issues, swelling, dry skin and heart palpitations.

### **Fatigue**

The major complaint among patients with thyroid cancer is long-term tiredness and fatigue, which is extremely common:

And I do still have fatigue. I don't have the energy that I used to have. But apart from that I don't have any other symptoms really, (...). But because I am still quite fatigued, I kind of feel that I lack the energy that I have, I kind of lack that spark for life that I used to have. NHS02int3

Participants understood that their tiredness is most likely due to a lack of a thyroid gland. For one participant, tiredness affects their career trajectory. She had to quit her new job:

I had to have second part of my thyroid removed and that was quite unexpected, so I accepted a job and then I was scheduled for surgery, it was 3 weeks before my new job, I was very tired, trying to get used to levothyroxine, I had a lot of migraines, I just had to accept that I was not well enough. Only in January I started feeling better. TC22

### **Neck pain and tightness**

In most cases, people have neck tightness and discomfort in the area for some time after surgery, but it improves. However, some participants reported problems with their neck movement even a few months after the surgery:

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

For others, tightness is not a big issue. Some people can only feel it occasionally or it is almost completely gone.

### **Voice problems**

Most participants in the study have no long-term voice problems. Even if there was some croakiness initially, it improved in time:

Yeah, my voice is fine, I did have a bit of a croak, it was slightly more scratchy after the surgery but it is gone now, I have no problem shouting. Yes, so no problems there really, they did a good job. NHS02int3

However, a small number of participants have long-lasting problems with their voices. It is especially troublesome for those few participants involved in singing:

It is still not back, calling my cat in the evening is a struggle, I used to sing in a choir my voice is a bit wobbly. I can sing along, it was not professional, I can still do karaoke, it is not awful, but it is croaky. TC14

The second participant involved in signing said that it took one year to get their voice back, but it is still not the same and affects the singing performance.

## **Permanent swelling**

Swelling of the neck area following an operation is common. However, for one participant, the swelling became permanent:

I now have a condition called lymphoedema, so I now have sort of permanent swelling on the right side of my face and neck, so that was literally never mentioned before the op, that never was discussed because it is quite rare. Mine is permanent, and now I have treatment for that, so every two month I have to have a massage, a face and neck massage, to try to drain it. But there is a distinct difference between both sides of my face now, which is you know, a side effect but not one that was ever discussed with me before the op. and I've heard about lymphoedema because it can happen after breast cancer, because you lose your nodes, but it was something that I was not expecting.  
TC07

The above participant expressed that although it is still a problem, they are not a person that puts much importance on looks. Still, the participant was expecting to get married shortly. Moreover, they already planned to inform the photographer to only take pictures from the side where there is no swelling. This long-time complication significantly affected the life of this thyroid cancer survivor.

## **Heart palpitations**

One study participant reported heart palpitations:

I do have weird things as well, my arms feel like jelly, I get heart palpitations as well, weird feeling in my chest, which was quite bad last one or two weeks. And I am thinking if there is something else wrong? I am really not feeling well at all(...). I get unpleasant symptoms from the medication such as heart palpitations, shakiness and nausea. NHS02 second contact

For this participant, time did not improve the issue:

'But it is giving me symptoms. I have heart palpitations; I have a rising heartbeat quite a lot and dry skin. It's not got better, I've still got rising chest.' NHS02int3

Participants' less common symptoms associated with their treatment include dry skin, often cold, hair loss, new onset of hay fever, shakiness, problems sleeping, swollen neck, and sweating. Some of the symptoms are related to surgery (voice problems, swelling) and long-term hormone replacement therapy (fatigue, heart palpitations, dry skin). There seem to be no long-term side effects of RAI apart from one participant whose salivary glands can be sore when dehydrated.

## **Changes in fitness level**

Most participants regained their original fitness levels. Only a few noticed decreased physical fitness:

‘Yes, I am going for walks, I can manage that still, but I can’t do other things, I used to run, do weight training, that sort of thing, but at the moment, I am walking and that is it.’ TC03

Some participants had to cut back on their leisure and sport activities:

(...) We used to go out walking a fair bit. After the surgery we got another dog. That got me out and about. But unfortunately, I don’t have the energy to take her out, I’ve been out a few times but that is it. This treatment is taking its toll on me again. TC05

As seen above, many long-term physical symptoms can also impact people's lives. Moreover, the activity level can also be affected, having a major impact on the daily lives of people with thyroid cancer.

## **4.4.2 Metastasis and Persistent variant of the disease**

### **Dealing with metastasis**

Most participants were cleared of the disease when the study was conducted. However, some participants had metastasis of their thyroid cancer. Naturally, this provides even more worry and anxiety for participants. One participant had metastasis in their spine. The pain in their back was the catalyst that eventually led to the diagnosis of thyroid cancer. Another participant found out she has small suspicious lesions in their lungs:

From the CT scan, and I didn’t have an appointment after that, so they just told me just before the surgery. (...) They couldn’t do anything, I don’t understand why they told me right before the surgery, they couldn’t do anything, they said it was very very tiny and there was nothing to do then (...). I was very, very scared. TC09.

The participant was very distressed about the further developments:

I wanted to carry on with my life, I wanted to get pregnant, but the endo said that I can’t do anything, it was like my whole life was on hold. I broke down. And the surgeon was there, and he called me in, and he said I don’t know why you are here, I don’t know what you want from me, and I was like I didn’t want to come here, I was referred to surgery, what is going on, I was so shocked. He said if you want me to take them out, I will take them out but there is no point, he didn’t understand why I was crying. I was crying because I wanted my life back. TC09

This patient was pregnant at the time of the interview, and there is nothing that the doctors can do regarding the treatment due to pregnancy.

### **Persistent disease**

After three rounds of ineffective RAI treatment, this participant was told that her cancer is persistent:

I am not overly worried, I think if it is still there, I think she will just want to monitor it, I am a bit frustrated, I am not particularly happy with just monitoring it, I don't want to live with it. I don't want to wait and see, it is like waiting for a time bomb to go off, you may just wait, and it will come from somewhere else at that time. (...) TC18

As seen in the quote, the participant is frustrated with waiting and worried about the disease, but their pragmatic attitude helps them to cope with the situation. Another patient has incurable thyroid cancer metastasis in the lung; however, this participant has a remarkable attitude and resilience:

It could be life limiting because it is in my lungs, that is probably they are slightly worried about it. But I could be run over by a bus tomorrow. You never know. I never sort off think 'oh, there is something growing inside me, the end is near' sort of thing. I carry on every day, and I do what I want to do. Nobody knows when they will die. I never wake up thinking 'oh, today may be my last day' I think 'oh what do I need to do today. TC16

This represents a situation when the clinical characteristics of the disease do not directly impact on experience of people. These participants remain very resilient even when facing with more complex cases of thyroid cancer.

### **4.4.3 Dealing with surgical scar**

Although most of the study participants were cancer-free at the time of the interviews, a few participants still battle with the disease. Most participants explained that their scar has healed well and is not impacting their life:

The actual incision is lovely, you can't even tell, you kind of have to look for it to know it is there kind of thing, yes really good job done on that. I had some aftereffects after the radioactive iodine with my salivary glands. TC18

Even after two surgeries and staples, the scar can heal neatly. Most people have their scar in a skin crease; hence it is almost invisible. One participant explained that although the scar does not bother them too much, they tend to compare their scar with other thyroid cancer patients.

Interestingly, all male participants were quite satisfied with the look of their scars. However, for some of the female participants, the scar proved to be a distressing topic:

(...) I didn't have any idea how, when I say I have a big scar, I mean I have a huge scar, that runs from my left collar bone all the way my neck to my right ear, so when they previously discussed what the incision will look like, it was still a big surprise when I woke up from the anaesthetic and looked at the mirror, I didn't have like the sense 'oh crikey' I didn't think it was going to be that big. I didn't know they were going to use staples, and it looks very bad when you look in the mirror. TC07

Effects of the scar on work were also worrisome for some:

(...) Yes, my major worries were the scar because I was thinking, yes, we are taking your thyroid out, it was fine, it was benign, but you got the scar, you know, I was not better off. So, there was the scar and my voice because I am self-employed, it was like how much work am I going to lose, from not being able to work because of this, and how much work am I going to miss out of it, because they are not going to like my scar and the appearance. TC03

Other problems related to the scar that participants of this study reported include some tightness post-operatively and a little lump in the scar area. Most people were advised to massage the scar to promote healing, decrease tightness, and minimize scarring. However, a few participants think they could have received more advice regarding wound care and scar.

#### **4.4.4 Experience of COVID-19 during and after the treatment**

##### **Experience of treatment during COVID-19**

Several participants in this study had their operations during the COVID-19 pandemic. Participants who had their treatment during the pandemic had to isolate themselves for two weeks before and one week after. They reported issues included being discharged early, having to isolate, being advised to come in alone, isolation when in hospital, not being allowed visitors, and having difficulty communicating with staff wearing Personal Protective Equipment (PPE). In addition, two participants expressed that the experience was surreal due to infection control measures in the hospital:

(...) The second time was a little bit like an out of body experience, the only way I could go through it was to detach myself from what was happening. I couldn't think about the next step, I just literally lived in that minute, because my dad took me in for the surgery, and he could take me up to the ward, but then I had to sit on my own and wait so all of that was hard anyway. And everybody had their masks on, and that was adding to it, and to actually go to the theatre, I had to wear a mask, and walking down there, normally you go to a pre-anaesthetic room and you talk to lots of people and they make you feel relaxed, they couldn't do that so we had to bypass that room, I walked straight to the theatre, and lied down on the cold black slab, they were all in full PPE, they had like full on gas masks on, old-fashioned gas masks, and they tried to socially

distance from each other, (...), and people were trying to talk to me but I couldn't hear, and I couldn't speak back because of the mask, it was a very bad experience that one.  
TC03

Some participants found it very difficult to be in the hospital during a pandemic. Below there is the account of the experience:

When I came back to the hospital, they couldn't confirm that the ward was covid free, I literally broke down, I had panic attacks. I was in hysterics, I was screaming like I was not going to that ward, the brain is so strange I could see, I was delusional, I could see bacteria. It was definitely severe anxiety, I was thinking the air isn't clear, I want to breathe clear air outside. I didn't want to be stuck there with all those people that I don't know. Patients didn't wear masks; nurses were wearing masks. I am not sure, I was told that everybody was wearing a mask, the only time I was taking it off was to quickly shove my food in, inhale it, and then put my mask back on, I didn't want to use the toilet and I didn't want to walk around. If the virus was not there, I wouldn't have had so much anxiety, it would have helped. I am sure I could speak for a lot of people; I've seen a lot on there, about people not wanting to do things like that, it wouldn't be a problem if the corona was not around (...). TC17

Isolation was one of the issues raised. Due to the pandemic, participants could not have visitors, which was also distressing. On a positive note, participants reported some positives of having their treatment during the pandemic:

But now I am glad it happened at the same time, cos nobody had to know what was happening, cos normally I would be travelling so I don't have to get questions oh why she isn't here, why is she not working etc., I am quite glad that, because everybody is not working, I can sort of recover in peace, and I started my business it is quite nice that it had to stop I didn't have to turn down customers, and I had time to think about new things, and have ideas, so I am quite glad, I am ok with the whole COVID thing.  
TC03int1

As seen above, treating during a global pandemic had additional challenges to an already difficult experience. The challenges included isolation, not being able to have support for family in the hospital and difficulties communicating with HCP in the hospital due to use of PPE.

### **Experience of a pandemic for patients whose treatment was completed**

Some participants who had their treatment before the pandemic started felt it did not affect them. People were just getting on with government recommendations and were being cautious. Participants were also reassured that having had thyroid cancer did not put them at higher risk of getting infected or having more severe disease. Participants that had just finished their treatment before the pandemic felt lucky that they had managed to complete their treatment, avoid delays, and avoid having to go to the hospital during the pandemic:

I feel incredibly lucky and fortunate to have both operations out of the way and radioactive iodine treatment out of the way now. NHS03int2

Some of the study participants got a corona virus infection and had to deal with additional stress regarding the disease. Several people were worried about COVID-19 and felt vulnerable due to thyroid cancer. On the other hand, several participants were vigilant and more careful due to their cancer:

Yeah, I am probably more cautious than other people. My daughter thought that I was being a bit paranoid when I first came back from the hospital, I was like oh, have you wiped door handles, have you wiped light switches, things like that, so yeah, you are a bit paranoid about it, you can understand why. I suppose I am a bit cautious; I don't go out really anywhere, apart from to exercise, I do go out to exercise, and I do go to the chemist, just to pick up my prescription. It gets me out and about, but any kind of like supermarket shopping, my husband has done it all. TC01

Lockdown was also tricky for study participants. The global pandemic and lockdown made many people feel isolated and distressed. However, a few people stated that they had enjoyed lockdown:

Maybe it was a blessing in disguise as I did enjoy my retirement, the coronavirus was a bit of a blessing for me, because when I was off my treatment, I felt brilliant, I had lots of energy I was able to do lots of things in my garden. TC05

Some participants stated that the pandemic gave them a distraction from their cancer. Most participants said that they coped well, given the circumstances. Although there were inconveniences, mainly due to social distancing and the inability to see the family, most participants felt optimistic about the future. They are waiting for the situation to improve. One participant expressed that having gone through cancer gave them the resilience that helped them cope with the pandemic:

I've been fine through lockdown, most people haven't had a major life crisis in their life, and I had, and the only thing you have to do is stay at home and wash your hands, so like to play an active role in your treatment, you can play an active role in COVID, you wash your hands you don't go out, you stay inside, once you've done these things, there is nothing more to worry about, so I had friends and family coming to me and I gave them that kind of talking, you can't play an active role in this apart from washing your hands. That acceptance is really useful. TC07

Participants were trying to actively spend their time in lockdown, going for walks, doing sports, gardening, and catching up with friends and family online. Some participants continued working from home or were classed as key workers and had to carry on working.

To summarise, the covid pandemic proved to be an additional challenge for many participants. It created more worry and distress. Especially patients that went through treatment during the

pandemic faced many challenges. However, participants felt reassured when the statement was released by BTCT charity that there is no evidence that patients with Thyroid cancer are at increased risk for Covid or its complications when compared with the general population.

## **4.5. Experience in Disease management**

### **4.5.1 Experience of NHS management of the disease**

As explained in chapter one, treatment for thyroid cancer has few steps and is managed by teams including endocrinology, oncology, nuclear medicine and surgery. However, the treatment can be lengthy, and there are required waiting periods between treatments. Below are the accounts of participants regarding their experience with disease management. Most participants have an appreciation and a level of trust for the NHS and their NHS care team:

‘NHS is fabulous I don’t care if facilities are sometimes substandard.’ TC14

However, there were complaints against NHS facilities or managing the disease. Some complaints are regarding medical errors and some regarding system failures and disorganisation. The medical errors include the surgery on the wrong part of the thyroid. Two participants had surgery on the wrong part of their thyroid. It may be an effect of self-referral:

And when I met the consultant that, it wasn’t him that took the wrong thing out it was his junior, and I had to use a swear word with him, I said you fucked my neck, and he is like you are being over dramatic, you are being over the top and then he touched my neck and he said oh my god!!! And then he realised. TC07

Organisational complaints include lack of organisation and preparation for appointments and cancelled appointments. Some appointments had been cancelled due to the pandemic. Few participants mentioned that missed or lost letters prevented them from attending appointments, prolonging the waiting. Another issue mentioned by a few participants was long waiting times between treatments. While some patients mentioned that everything happened very quickly, others were struggling with long waiting times between treatments:

The only negative and it's not really a negative is that things happened so fast at the start, now that we are into: it's three weeks till then or it is five weeks till then. It now feels that things have slowed down. But that's all planned. NHS01int1

A few participants were dissatisfied that they had different parts of the treatment in different hospitals of the same trust. In addition, this participant, due to being managed by many teams, was confused about whom to contact regarding concerns:

(...) Had to 'push their buttons' for referral to speech and language therapy, ENT nurse said 'it is not my baby', oncology nurse said 'it is not my baby', I said 'it has to be someone's baby, it is my voice'. I had to be very persistent to get the referral, I couldn't talk I couldn't sing, I thought 'it has to be someone's baby', (...). Having different parts of treatment in different hospitals is hard, who to call, who to contact. TC04

Different parts of the health care system have other troubles communicating effectively:

'GP always battles against what the hospital staff say (...). I mentioned it last time and my oncologist gave me a card from BTCT.' TC15

Other complaints included cancelled surgery due to COVID-19. It was distressing for those affected and disturbing in life and work. However, sometimes, it is unavoidable and in the patient's best interest due to emergencies, being short staffed and some surgeries take longer than planned (from the author's clinical experience).

Overdiagnosis was a complaint raised by one of the participants. They are confident they should not have had her entire thyroid removed. The participant is sceptical about having had cancer. This opinion was shaped by their research as well as what some health care professionals said:

I think as well, I spoke with a few people about papillary cancer, I think it was a radiologist actually that said that most people have a bit of papillary cancer in their necks, if you look at most people thyroid you would find parts of papillary cancer. I think if you had a big lump like I did you should have it removed. But papillary thyroid cancer is becoming more common because more investigations are being performed.  
NHS02int3

After the second surgery, it turned out that that part of the thyroid gland had no cancer:

(...) Not having the 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

However, the participant understands that maybe it was a good decision. As seen, participants were very understanding that the waiting times are sometimes unavoidable. Moreover, in some parts of the treatment, a longer waiting time is necessary due to the nature of the treatment.

As discussed above, although the majority of participants in the study were happy with managing their disease by the healthcare system, there were some complaints regarding waiting times between treatments and the treatment being disjointed due to the involvement of many clinical teams, and operations being wrongly conducted, cancelled.

## 4.5.2 Thyroid cancer patients' experience of information provision

### Information provision at diagnosis

Being well informed was very important for all participants. As a result, most study participants were given sufficient diagnosis information. However, many reported having difficulty retaining the information received on diagnosis:

It didn't really sink in really to start with, because they sort of give you a lot of information, I mean. He went through the information on what the treatment would be, he did say don't worry if you cannot remember it well, just remember it is treatable. You can always get back in touch and ask questions, and stuff. TC01

A few participants said that they were not provided with good information:

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

Not providing information made participants look up results themselves using mainly the internet. A few participants felt they did not receive information after diagnosis but a long time after.

### Gaps in the information provided

Although most participants felt prepared, several participants stated that the information they were provided did not prepare them for the treatment:

(...) Not really no, 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 prior to 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

Some participants feel like the health care providers played down their diagnosis:

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

It made participants feel unprepared because they did not expect the side effects as the possibility of it was not communicated before. Some participants felt they were prepared for some aspects but not for other aspects of the process. A common complaint was the lack of information about taking levothyroxine. Moreover, some participants said they found information that they provided too general and not thyroid cancer specific. Other participants

mentioned that they were not prepared to deal with stiffness, physiotherapy and exercises, how unwell they would feel after the operation, swallowing after the operation, and the length of follow-ups. As seen above, the three significant gaps in information provision were the physical aspects following surgery, including long-term physical symptoms, psychological aspects of the cancer journey, and levothyroxine information.

### **Sources of information**

Most people had their initial information from their consultant, the doctor delivering the diagnosis or a thyroid cancer nurse specialist. In addition, almost all patients received information packs from their care team in the hospital. Packs included BTCT information packs, including their DVD, Trust specific information, the information pack from Macmillan, and information from the British Thyroid Foundation. Most people were pleased with the quality of information from BTCT, and their DVD was very useful to many participants:

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

When patients have questions, a nurse specialist is the first person to contact. Some people who did not have a thyroid cancer nurse could ring a Macmillan nurse or an ENT nurse in their hospital or contact their consultant via their secretary. A few participants mentioned that if they have any questions, they are more likely to ask the online thyroid cancer community on Facebook or the Internet in general. One participant knew another person with thyroid cancer and sought information from that survivor.

### **4.6 Psychological health after thyroid cancer**

Physically, most patients recover well from treatment. However, the psychological effects of having thyroid cancer can be extensive:

‘(...) But it does affect my entire life, yes, it is, it is really bad, it is awful’ NHS02.

For most participants it was the first serious health challenge that they have experienced in their life:

I am not the kind of person that is going to the doctors all the time as well, until I had this thyroid lump, I don't think I ever was off, never had a sick day, never been ill before. For me to feel bad like this, you know, it is really quite significant. So, you

know, it is something I just have to try to get through I suppose. (...) And it is quite hard to stay positive and carry on as normal (...). NHS02

Most participants reported improvement in their mental health symptoms with time. Especially when treatment was completed:

I did not want to be stuck, my anxiety was horrendous, mentally I am a 100% better, in all fairness even before I found out about cancer and compared to now, mentally I am in a better place. I don't know, my whole mindset has changed, but the CBT has helped definitely, just knowing that I will be ok, and I am moving forward, I don't want to be stuck in the past, and thinking about it and talking about it. TC17int3

Many participants expressed that thyroid cancer no longer has a major part of their life:

I think as the years go by it has lesser and lesser, and actually before it was on my mind every day and I was looking at my scar because initially it was very red and it stood out, but actually time goes past, weeks even and it doesn't cross my mind. Don't get me wrong it is still there, you just kind of learn to live with it better, it seems to be my mantra. TC1

With time, thyroid cancer stops dominating people's minds, and they can move on from experience.

#### **4.6.1 Anxiety and mood swings**

Several participants reported an increase in symptoms of anxiety and depression:

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

Sometimes mental health issues due to thyroid cancer lead to very negative thoughts:

I actually wanted to give up. As bad as that sounds. I've got two young daughters; they are 3 and 5. They are hard work. TC17

For some, it is not only health anxiety that increases but it transfers to other aspects of life. For example, one participant explained that they became very anxious about other aspects of life like general health and work. Some participants needed to seek support to aid them with coping with anxiety. This will be discussed later in the chapter.

For some, it is the treatment journey that induces mental health symptoms that needed to be addressed pharmacologically:

I was feeling very awful for a very long time. I don't know why they waited almost 10 months to let me see endo, when all my blood tests were coming back off. Physically, I am absolutely fine. (Psychologically) for a while I was feeling really bad, I had to take some diazepam, I just couldn't. For me it was the battles with doctors that were the worst. (...) Then I just wanted to continue with my life, I know it is a little bit reckless as I can't be treated now, but I couldn't just wait for them any longer, nobody knows what to do anymore with my lymph nodes, it is really weird. TC09

A less common symptom reported by participants was mood changes. However, this problem was very significant for this participant:

You know, when you have your thyroid removed, thyroid regulates all your body organs, so it actually affects your whole mood. And people who have underactive thyroid find that they have problems with mood. You know, and I do have days when I have low mood. (...). I've never had any problems with low mood before. I've always been happy and optimistic. I must say that since having this diagnosis. NHS02int1

Moreover, although the situation improved with time for this participant, they do not feel the same energy for life that they felt before diagnosis:

I am definitely a lot better than I was. It is good you mentioned it, I kind of forgot how low my mood was. Yes, I feel so much better now. But because I am still quite fatigued, I kind of feel that I lack the energy that I used to have, I kind of lack that spark for life that I used to have. NHS02int3

#### **4.6.1.1 Reasons for increased anxiety during and after treatment**

##### **Health Related worries**

Most people are worried about future recurrence and possible future metastasis:

But on the whole, what is kind of scary is that there is a couple of people who had it recurred, one lady had it recurred in her skull, another one in her chest. And seeing those, they make me a bit worried. I'm kind of used to the idea that I will always be worrying about it, this kind of put me off for a while. TC01nt3

A small number of participants were worried about the increased risk of getting other cancers due to RAI treatment:

I mean I am quite an optimistic person which I think helps, what worries me is that when you have had one type of cancer the risks of getting another cancer are higher apparently, and that sort of thing, so that worries me, what else am I going to get. TC03int1

Participants were worried about metastases, poor health outcomes, long-term side effects, getting other unrelated cancers and death.

## **Worries about the future**

Several participants were worried about their future fertility. For example, one participant worried if it would mean it would be more difficult to get pregnant:

And I am worried whether me not having a thyroid will mean it will be more difficult for me to get pregnant and have children. And you know, it is all just shit really.  
NHS02int1

Another participant was more worried about potential risks to her baby. For one participant, the experience of the NHS during thyroid cancer confirmed their decision not to have a child:

That was not something that we were planning to anyway, certainly it was not something we were planning anyway, there is absolutely no way I would have a child with the NHS, there is no way I would get pregnant and give birth to another human being and trust the doctor to do that safely, no chance in hell, that sealed it. We weren't that keen anyway but that kind of sealed it, there is no way I am doing 9 months of treatment with the NHS and then looking after a baby, no way. TC07

Some participants find the difficulty in making plans distressing, especially when the treatment was still ongoing:

And you, know it is just a bit awful, you can't make plans, like I can't make plans with my friends for Christmas because I don't know when my radiation date is yet. I don't know, I can't go on holiday. I haven't been on holiday for a long time, and I was like, I wanted to go on a holiday this autumn, because I had, but I had to have surgery, I already had a ton of time off work for being sick, I don't really, I feel I can't really ask to go on holiday. And I don't think I can go, you know, I don't know when I can do anything because I don't have any dates, or I don't know if I am going to have more scans or, you are just completely in limbo for a long, long time. NHS02int1

## **Worries related to Follow-up appointments**

Because thyroid cancer can return even after many decades, most patients have lifelong follow-ups. The appointment usually consisted of an examination of the neck and a blood test to check for the presence of thyroglobulin. The majority of participants were reassured about having regular monitoring:

I guess you are always feeling a bit nervous, but the follow ups are pretty good really, because there is a marker there that can be detected if something is creeping up there, I feel quite grateful for having those. TC22

Participants were reassured about the monitoring because if cancer returned, this would be picked up very quickly. It makes patients feel looked after. The participant below agreed that it is a little inconvenient but necessary:

Yes, I would rather not have any appointments, but I am happy I will be monitored, I am very grateful as it is needed. My first follow-up appointment was supposed to be after six months, but it was cancelled, and I didn't have it till 11 months after. TC12

While some people seem not bothered by follow-up appointments, most people get a little nervous, especially before their appointments:

Yeah, I do get nervous beforehand, even today I was sitting there thinking oh gosh, my heart started pounding away, I was like oh no. But it was fine today, you know, they are very good at explaining everything, but you kind of always, at the back of your mind, are they going to tell me something bad, something hasn't gone as well as they thought or am, yeah, I think you just kind of learn to live with it I suppose. TC01int1

One participant was worried about whether his monitoring appointments will be stopped at some point:

Yes, I am worried, I am worried that I won't be followed up after 5 years, because my consultant was saying that he probably won't need to follow me for longer, oh my god, 5 years that's not a lot. TC13

Some people with half of their thyroid may have regular appointments to monitor present nodules. However, occasionally other health problems overshadow thyroid cancer, as they have more impact on quality of life. For example, one participant is more worried about their hip problem than anything with thyroid cancer.

#### **4.7 Acceptance, moving on and helping others**

Following the treatment, most people want to move on with their lives. Many talk about acceptance and coming to terms with the new reality. People accept the fact that the worrying will stay with them for a long time, that there is always that thought at the back of their minds. However, they accept it as a part of their new life. One participant explained that they sometimes allow themselves to feel sad as the ability to feel negative emotions allows the presence of positive ones. One participant said that they learned self-compassion, and it helped them to accept their new reality. Another patient felt grateful when they had a good day and lots of energy. Another one was grateful for their partner and supportive family. Some participants felt that gaining knowledge about their condition was a significant part of coping. All the above are attempts to move on with life in their new reality.

You know, I think we will just move on. (...) You know, hopefully, it will be all uphill, going upwards. Other side I suppose, if it did recur somewhere, I will be able to say, I've been through it once, I will be able to do it again. TC02int2

For some participants, life after treatment returned to normal:

No not at all, business as usual (...) But I am more than happy with the treatment that I have received and that I can carry on pretty much like normal. NHS01

Back to normality was described by quite many participants. However, a few people mentioned positive changes that had happened to them:

But it also changed me in a good way, I feel more appreciative, I know it sounds cheesy, but it just makes you appreciate more, and it puts into perspective what is important in life. For me being happy and healthy is important but sometimes they are things out of your control. I think from that point of view it made me work harder on being happier and spending time with friends and family when I can. I don't know, I feel different in a sense that I have grown, became more mature, I think when you experience something like that, you know, shocking and life changing it just means that maybe you are more prepared for things. I think if in the future something major happens I will be more prepared for it, because I had this experience.. TC11

Another participant explained that they appreciate people more, and their relationships with others improved. Finally, one participant mentioned that the experience taught her a lot of valuable skills:

I know how to work the NHS now. Like, my friends are like, 'Oh I haven't got my letter yet regarding my appointment what should I do?' I am like 'right you have to badger the secretary, get on side with the secretary, they are the ones with all the power.' I feel definitely I have more tools in my armoury. TC07

Other sets of changes that participants reported are positive changes in lifestyle and health as a result of the experience with thyroid cancer. As well as being more mindful about health:

I feel like I will just keep check myself, looking for lumps, I will be very vigilant and going to my smear PAPs and things like that. And if anything changes, I don't have any qualms about going and getting checked. TC21

This, in turn, results in leading a healthier lifestyle:

I am trying to eat healthier, I wasn't eating unhealthy at all, but now I've noticed I am not really good with dairy, I don't even like the taste of dairy anymore. We both want to start eating healthier, less red meat, more fish and chicken, at least it makes me feel good that I am doing something, trying to eat healthier, I don't know if it will make any difference or not. TC01int3

Another common change that thyroid cancer triggers a desire to help others. Several participants felt empowered to volunteer and help other people:

(...) And now I am a volunteer, and I am a trained listener to let people talk and offer suggestions. That area of my life would not have happened. I am supporting people, helping them. Helping people is therapeutic and giving back. TC04

A few other participants got involved in fundraising for the BTCT charity to support them. Moreover, giving back to others was one of the reasons participants were willing to take part in the study, to increase understanding of the disease:

And, you know, after everything I've been through, it is hard going back to work, your life was just upside down, it was just. But it is not a common cancer, is it, it is not a cancer that you see on the tv, or cancer people do a run for, and I just think that people think you had the cancer cut out, why can't you go to work full-time, why are you tired all the time. Oh, you know, you could have worse cancer than that. That is why I was really keen to kind of do this, because I am always very keen for people to understand really, yes people, it may not be the biggest cancer, it is increasing quite rapidly isn't it, so. TC06

Also, the willingness to participate in this study was underpinned by the desire to help other people with thyroid cancer and to show other sufferers a positive perspective:

I think I just wanted to show a positive perspective. I thought it may be good for you, because when I log in to internet forums I never join in, as what am I going to say, I am fine!? But then you should really, because when people are just being diagnosed, they may want to hear this, so I wanted to take part in this, although I never get involved but I thought this time I will get involved in this. I want you to have a spectrum, I am sure you have people who had it worse, you would need someone that had a positive experience. TC20

To summarise, the psychological health of patients with thyroid cancer was significantly affected. Most symptoms related to psychological health improved in time. Anxiety symptoms were the most common. Participants of this study worried about recurrence, metastasis, other unrelated cancers and long-term physical symptoms. When relevant, participants were worried about their future fertility. Follow-up appointments and the need to be monitored for the rest of their lives can be reassuring and worrying. Following the treatment, participants described the process of accepting that the thyroid cancer experience is part of their lives. Moreover, the need to move on from this is also evident from the participants' accounts. Many described processes of transformation. Three main areas of positive transformation following the treatment for thyroid cancer were a more positive and appreciative attitude to life and other people, adapting hellfire lifestyle habits to improve health and actively helping others through fundraising, volunteering, and participating in thyroid cancer-related research.

#### **4.8 Coping with thyroid cancer and coping strategies**

Participants were asked how they felt they were coping and what coping strategies they used to assist them. Participants had mixed views about coping. Although some feel they are coping well now, looking back, some are still struggling:

Remarkably well actually, since I lost weight and I got my head sorted, I cope with it very well, it never bothers me, I did slip out a couple of months ago due to my medication being changed because of my weight loss, and they adjusted my medication. And I was thinking why we are going back to those times when I was tired and wanted to sleep all day. I sort of worked through that and got on top of that again. TC16

Some are trying to move on with their lives and not think about thyroid cancer too much:

(...) After I received the diagnosis, I went back to work and carried on with life. I didn't think too much about it. I read that it was one of the easiest things to go over, it didn't faze me at all. TC16

There were a few different themes in the participant's account. When asked about coping, many participants talked about support from their family, friends and health care professionals. This will be discussed later in the chapter. This section describes personal strategies people used to cope with the disease. One participant explained his coping strategy as dissociation. For the participant below, pregnant with twin children just before treatment, their busy family life provided a distraction from cancer:

In a positive way they were like a distraction, because they didn't know, they were just babies, their needs were still the same, I couldn't hide under the duvet I had to take care of them, but yes it was a very worrying time. TC21

Having good quality information assists with coping. Even if the information was self-sourced:

'I helped me going to different websites and reading forums, chatting with other people, it helped me to go through it'. TC19

All the above are attitudes and active actions in order to improve one life. However, participants also did some actions to make themselves feel better. Those actions used by participants to try to cope with their disease are with the help of music, doing activities like yoga, mindfulness, knitting and even simple life pleasures like watching TV.

#### **4.8.1 Cultural factors and coping**

As discussed in Chapter 2, culture is a set of attitudes, beliefs, values and practices, which can assist in coping with disease or hinder the coping process. There was little ethnic diversity among the sample, with one participant describing their ethnic origin as 'White-other' and the remainder describing themselves as 'White-British'. There was also no discussion of religion, although this was a factor that was not specifically asked about. However, one participant appeared to indicate a belief in something beyond the material world when explaining how losing weight made her lump visible:

So, everything happens for a reason sometimes. Maybe something was telling me to lose weight and get healthy. TC01

Others suggested faith in themselves by identifying characteristics that they felt had enabled them to cope. One discussed their optimistic attitude, together with engagement in cultural activities, as a positive factor in their experience:

I think my attitude played a big part, I think I was really convinced from the get go that I will not die, that for me meant that I was not waking up in tears in the middle of the night, that helped a lot, I think, I like to write poetry, that was quite helpful, but I've never been someone that sat and thought 'oh, what songs will I play at my funeral?', I know that some people do that and for them this is a coping mechanism, for me it was just I was 'I won't die because I am so young. TC07

Another identified their positive attitude as being a beneficial factor and indicated that their consultant had similarly pointed to the value of this attitude:

My experience was unbelievably positive; my consultant thinks part of it is because I am such a positive person. I didn't even park in places for oncology patients as I didn't really think I had cancer. But I think other people have worse cancers than me so I was always parking in normal parking spaces. My consultant said that it didn't help with diagnosis but it helped with the process of being a positive person. So, I feel sometimes I feel it has been too easy and sometimes I think what if it comes back somewhere else. But it has been absolutely fine. TC20

For another, it was their practical approach that was an important tool to help them cope with their experience:

(...)I was straight into planning mode, I was on the phone to my consultant's secretary and I was 'I want to have this surgery, I want it scheduled, I want a date by the end of the week'. Because that was just my way of coping I suppose just like, you know. Yeah, knowing what was going to happen. TC06

Similarly, one participant suggested that it was their methodical approach to the steps that needed to be taken that prevented them from dwelling on the possible consequences of their illness:

I try not to dwell on it too much. I am kind of methodical, I am like 'oh, let's deal with that, let's do that next' and trying not to think about it too much. TC18

The idea that there can be a stigma attached to illness – a cultural factor discussed in Chapter 2 - was evidence in the accounts of some participants, manifesting itself in the form of embarrassment. As one participant put it:

Yes, I actually felt, I feel really silly, but I didn't tell many people because I felt embarrassed, it was almost like embarrassment in my body I was really disappointed in my body for letting me down. It is funny to think back on, but that was the main emotion I felt for a long time, just disappointment with myself. TC13

So there were cultural factors that affected the lived experience of the participants. However, these were less frequently discussed than a range of other factors.

#### **4.8.2 Support- family and friends**

##### **Family support**

Family support was essential when experiencing an adverse live event like thyroid cancer. Most participants felt very supported by their families:

If I didn't have them and family support I don't know what I would have done. Yes, they have been absolutely great, and I know they will be whatever happens, even if I go back and the results aren't what they are supposed to be I know that I will be ok, I've got my oncologist I've got my doctors, I've got my family so I know I will be ok, I will be fine. TC17int3

One of the main sources of support for participants was their life partner:

I think I surprised myself, my husband was really good at keeping me positive and keeping me going, we went to a show the weekend I came out of hospital, this kind of thing. I thought I'd never manage that, but I surpassed myself. And if it wasn't for him I don't, I would still probably be like I can't do this I can't do that. After the last treatment we went away twice, on holiday, we had good times. TC05

Participants valued their partners for their presence, moral support, keeping them positive, taking them places, their company at appointments, and financial and childcare support.

However, one participant was broken up with by her partner during treatment as he could not deal with the situation:

I had a partner and we split up, um, he was, he was definitely somebody that was upset by cancer and couldn't deal with cancer, we split up during the treatment, that was very upsetting, very upsetting. He said you are not as much fun since you've had cancer. Yeah, at the time it was something that happened during a very difficult time and it made it more difficult. TC10

A few others experienced strain on their relationship caused by the stress related to thyroid cancer:

Yes, there is a strain there, because there is a lot of worry on both sides. And at times I think that we both can be a little bit short tempered. We are identifying when it is happening, and we are trying to resolve it, but we have noticed that once or twice, both of us will be a little bit short tempered with each other. We don't fall out. You know, it

starts to happen, we bring it down again. There is obviously stress in there, which you can notice (...). NHS01int1

Moreover, in couples with children, most of the childcare responsibilities during treatment and hospital stays fell either on a partner or close relatives like participants' mothers:

Oh yes that was all fine, my partner was here, he was in and out of work, and my mum was coming here. I really did have some rest though. I was there (at my mum's post-RAI) for 5 days, I tried to keep myself busy as much as I could. It was just sheer boredom. But then, I came home, things were back to normal, normal life. TC17int3

One participant's family situation meant that the nursery mainly provided childcare support:

My husband, (...), his mum was not being very helpful even to take the children to nursery. Their relationship is very difficult. She never asked about me or the children, although she lives around the corner. So, our biggest support really was the nursery. My mum is not involved with my children after an incident many years ago. I don't talk to her. She never showed any interest so we couldn't even ask her for help. Two people helped me, my two friends. And the nursery was great. Little things make a difference. TC12

The situation was easier for participants with older children.

The thyroid cancer diagnosis and treatment experience are also challenging for the loved ones of the study participants. Most of the time, family members react to the news in shock and fear:

Confused, worried, heartbroken, I've got my mum, auntie and my two sisters, they were very confused, we had no history of cancer in my family from both sides, and my mum was just destroyed, I think I would feel the same if one of my girls got something like that. She was trying to be so hopeful, bless her. TC17

Family members were worried about the treatment and the prognosis. Moreover, the mental health of family members of people with thyroid cancer can be affected:

My mum lives in (name of foreign country anonymised), her reaction was very bad. I had to remind her that it is me who has cancer. She was very upset that she can't be with me all the time, and she made it hard on me. I had to remind her that it was me going through it. TC09

One participant's wife needed counselling to help her deal with her husband's diagnosis.

Other participants were worried about how the family would react to their diagnosis. Some were worried about telling some family members, including siblings and children.

Support from family was essential for participants of the study. Most of them felt well supported but not all of them, for some thyroid cancer impacted the breakdown of the relationship, while others experienced some challenges in their relationships. Thyroid cancer

diagnosis and treatment are also challenging for family members and can induce much anxiety, impacting the lives of participants and their whole families.

### **Friends' support**

Apart from family support, another important social source of support was friends. The majority of participants had the support of their friends:

They have been really, really helpful as well. Really kind and really supportive. Two of my friends that I went to university with bought me lots of things to take to the hospital with me, like a nice blanket, magazines, and a crossword puzzle, which was lovely of them. So, they have all been really, really supportive. NHS02int1

Participants appreciated their friends as well as work colleagues for being interested in their situation, sending them messages and calling them:

I've got friends from work, they were very supportive, we are sort of the same age, and we are a very small group. They supported me, and I have some friends in another part of the country and they stood behind me 100%. So, yes, I felt supported by my friends and colleagues and that is what got me through it. TC16

However, a small number of participants mentioned that some of their friends could not seem to handle their cancer diagnosis:

Something I noticed with people, not everyone was able to ask me how I was, some people just completely disappeared from my life, it is like they couldn't handle it, another thing was that people thought that, after my RAI was over, they just thought it is done, it is over, they don't realise that this is ongoing, I don't receive any questions about how I am doing, and it actually hurts a bit, it is still ongoing, it is still happening. TC09

One participant reflected that it could be because this participant's friends are young and had never come across cancer in their peers before:

Being young, getting this, being in my 30s, I am probably the first experience of illness by my friends of a friend with cancer. They may have experienced it with a parent or grandparent but being a first friend that had it, I think really scared and shocked people. TC07

Another participant thinks it could be because some friends do not take their cancer seriously as they see them looking "well". As seen above, support from friends and family is essential when going through thyroid cancer. Therefore, it was important for participants to feel supported by their friends and family. Some participants experienced disappointments in their family, friends and significant other.

### **4.8.3 Relationships with health care professionals**

Relationship with health care providers significantly impacts the overall treatment experience of thyroid cancer. A good relationship with the consultant positively impacted people's experience. Most participants were satisfied and happy with their relationship with their leading doctor:

‘So, I love my surgeon, he is like my favourite person outside my family and close friends, I think the world of him’. TC07

Essential qualities in a great consultant mentioned by participants were being kind, informative, communicating clearly and being approachable. While most participants praised their consultant for excellent medical care and information, other forms of support, information and psychological support were provided by nurses, especially the thyroid Cancer Nurse Specialists (CNS). Many participants found support from the thyroid CNS invaluable. They are the first contact person for many patients. They answer questions, refer patients to other services and support the holistic needs of patients:

‘(Name of nurse) is my guiding light and saviour if I really need anything I know she is just there on the other side of the phone.’ TC08

Some participants did not have the nurse specialist service available for them. In that case, their main contact point was secretaries, ENT nurses, or McMillan nurses. Due to the lack of a key person, a few participants mentioned that they were not sure whom to contact if they had questions about their specific case, which was distressing. As a result, some of them rang their consultant’s secretary for information. Also, some people did not know about the service till they did not need it anymore.

### **4.8.4 Forms of psychological support accessed by participants**

About half of the participants did not access any formal means of support. The other half accessed different forms of support, mainly charity.

#### **Counselling and CBT**

A few participants felt they needed counselling. Some participants accessed counselling offered by the NHS, and other were offered via charities. One participant used to have counselling

before their diagnosis. Most people who accessed counselling (a few participants - 4) found it beneficial:

After RAI I was in a very bad state. I had counselling and it wasn't about cancer it was about all of life. We are so lucky to have this charity, you get counselling or therapy. I chose counselling and they do reflexology or other alternative treatments. TC04

Even if it was just a few sessions, participants felt they benefitted:

I mean, again, I feel that I benefited from seeing a counsellor, that person is available via ION study so I am very lucky, and just being able to talk it through with her really helped and she helped me to set some goals and she helped me to clear my thinking so I don't catastrophize anymore, it was really very productive, even if it was only three sessions, it was really useful. Those three sessions just dealt with the issue very effectively. TC08

The experience of counselling is not always positive:

I had a few NHS sessions that I didn't find very helpful, I thought the setting was too clinical, I didn't feel warm enough, comfortable enough, in a room somewhere at the back of the hospital. She was friendly but I didn't feel like that sense of support from her, so I decided not to pursue that. In terms of charity support. TC11

One participant had a few counselling sessions but felt he did not need them. However, access to services was not very straightforward, people usually had to wait a few months for it to start, and some had to go through their employer. One participant accessed CBT therapy and was happy with the results:

Yes, I am still doing it, I find it really helpful. It has been working really well (...)  
I did not want to be stuck, my anxiety was horrendous, mentally I am a 100% better, in all fairness even before I found out about cancer and compared to now, mentally I am in a better place. I don't know, my whole mindset has changed, but the CBT has helped definitely, just knowing that I will be ok, and I am moving forward, I don't want to be stuck in the past, and thinking about it and talking about it. TC17int3

Only one participant in the study accessed help offered by a clinical psychologist. The participant did not think it was beneficial.

### **Support from Butterfly Thyroid Cancer Trust and other charities**

Most participants who accessed BTCT information, support or both, were very grateful. In addition, people found their website, information pack, Facebook group, Twitter, and DVD very informative. Especially the DVD:

'The DVD from Butterfly was amazing, but I should have received it at the beginning not after my whole treatment finished and only after me googling and finding butterfly.' TC04

The second way the BTCT supports people with thyroid cancer is by allowing them to talk with one of the charity ‘buddies’ and the founder herself, all of whom have personal experience of going through thyroid cancer:

(... ) But then the next day I was I can’t cope with it so I rung Kate from Butterfly, and I feel very emotional about it (crying), she was just fabulous, so reassuring, she said yes, the same type I had she said you will be fine, you will be fine. It was like. A cloud had lifted. Please don’t worry you will be absolutely fine. TC14

People praised BTCT for advocating on their behalf and supporting people to challenge their providers when appropriate:

To just help those who volunteer like Kate, they are the best people to talk to, they understand, and they have been through it. They will give you great advice, that is fantastic, go back to your doctor, this is unacceptable, they really help. The NHS is fantastic, they know, but the other things, psychological support they don’t do it. For them, ‘oh, it is thyroid cancer, you will be ok, off you go’. Things that you worry about, they don’t seem to have that fear. The volunteers you have for support are fantastic. TC14

Some participants preferred the email option, had email discussions with the charity and found it very helpful, supportive and informative. Moreover, some participants had treatment in newly decorated BTCT RAI suits and were very pleased with the effect. It improved the experience of the RAI treatment. Many people found support in charities, including Macmillan Cancer Support, Maggie’s, Trekstock (Young Adult Cancer Support) and local cancer support centres:

I was involved with TECK, they specialize in the support of young adults, they’ve been amazing. When I was diagnosed I did a bit of research to see what is out there, I don’t think there is a lot for thyroid cancer patients but also specifically for young people, it is like children or people that were 40+. And I found it difficult to relate to. So that charity I got involved with, I attended some of their events, they put me in touch with some people from the cancer community, which was brilliant, and I found some friends as a result of that. And they also have online support programs and videos that you can access for free. So that is brilliant. TC11

Charities, especially BTCT played an important role in supporting many participants in this study. However, as most participants were recruited via the charity, they may be more likely to be familiar with the charity and its services when compared to other people that may not have much to do with the charity.

### **Facebook group support**

Many people in the study became members of Facebook thyroid cancer groups and found them helpful:

I think, I am a member of thyroid cancer group on Facebook, and that has been, probably more helpful, because it was people that went through it, and you can ask questions like how long were you off work, and people will come back, oh I was off work for a month, so you can get an idea of what side effects there may be and how it will affect you. I think it was just anxiety because I've never had surgery, so... (...) Yes, yes, I think I've had more support from the Facebook group than from the nurses or the team from the hospital. TC01int1

Participants communicate with other thyroid cancer patients for advice, for example, about the low iodine diet, for support, for comparison of their journey, comparison of treatment management between different countries and treatment centres within the UK. However, not all participants find Facebook groups useful:

Well I looked on Facebook, there is one group I can't remember the name but oh my god what a lot of moaning. I don't post I just look. (...). And I don't find the Facebook group that helpful. But I follow Kate Farnell, I read what she posts, and really, as I said, (name of nurse) is my guiding light and saviour if I really need anything I know she is just there on the other side of the phone. TC08

One participant could not relate to other patients on Facebook groups due to their age. As a result, some people stopped being a member of the Facebook groups as they just wanted to move on:

I was but I stopped, there is a butterfly group which I am still a member of, but there was another one, which I stopped, I don't know, there is a point when you don't want to be thinking about it so much anymore. TC10

### **Support from other survivors**

A few participants were offered or requested to be contacted by another thyroid cancer survivor for support and information. One participant found it very useful:

And they put me in contact with another girl, and I spoke with her a lot, I still speak with her, every week really, because it is really nice to chat to somebody about how you are feeling. TC03int1

One participant regretted that decision as it proved to be the wrong choice for her:

A friend of a friend put me in touch with somebody that had thyroid cancer and she really wanted to help and be very, very supportive but she had a very different story to me, and she scared the living hell out of me. You know she just, it was really unhelpful, and I just, I really feel for her, she had a lot of issues and, I was told I will be there for one night and she said oh no you will be in for at least a week, so it was really unhelpful, and I can understand she wanted to be very helpful, but she wasn't helpful at all. She just had terrible bad luck, lots of delays and then her husband left her halfway through it and oh my god what a story it was. And I never spoke with her after that, she offered to go to the hospital with me but I was like oh you are not the right person to be with me. TC21

As seen above, people choose and try different forms of support and sometimes decide against utilising it again if they have not found it helpful. People are unique in their needs and opinions, and what works for one person may not be suitable for others.

### **Support from other health care providers (physiotherapist, speech and language therapist and GP)**

Sometimes patients with thyroid cancer are referred to another specialist to assist them with symptoms following the surgery. Unfortunately, many participants had no contact with and/or were not offered physiotherapy:

There was one aspect of it I was not happy about. I obviously had pain in my neck and shoulder, they didn't offer me any therapy, because I kept asking for it, but they said it will just go away. So, I found that, it was so bad at one point that my arm stuck to my side, I couldn't use my arm and it was getting worse, and I also found it hard to get speech therapy and when I got speech therapy, I was told by the therapist, oh I am sorry I should have seen you months and months ago, and it is such a shame that there was those delays, it just made life more difficult, getting better. TC10

Thankfully eventually, the participant did access the service and benefited from it:

'(...) it went on for 3 months, and it was helpful. It got to a point that I still can't put my arm over my head, but I can lift it up, I can use my arm again. It really did help me.' TC10

Some could not be referred because of the pandemic:

Oh, so the thyroid nurse she, normally I would be referred to a physio but because of the pandemic, I can't, so she told me some exercises over the phone, so I've been doing them, but you don't feel like they are as impactful as they would be if could see somebody. I am hoping it is going to get better with time. TC03int1

Very few participants accessed speech and language therapy support to support their voice issues. However, one participant said they were told it was very late and that they should have been referred much sooner. They were given exercises to improve their voice which seemed to help. Another participant had support from their GP with anxiety issues:

(...) Actually I suffer from health anxiety, so now I feel much better, but I went to the GP last year and I said that I worry a lot, and it has a massive impact on my life after, I just now, I think before, when you were in your 20s you just think you will live forever, and then I had this scare so now I am much more aware and I suffer really bad anxiety. So, I went there to talk about it, and that is how I found out there are so many other services that could have helped me when I was getting through it, things that probably would have benefited me a lot. TC13

#### 4.8.4.1 Reasons why some participants do not access any support

Almost half of all the respondents have not accessed any form of support available:

‘No, I haven’t. I didn’t feel the need, I had a few days when kind of being a bit overwhelmed a bit, but I sort of get over it and feel fine again’. TC18

Some participants are ready to access support if needed in the future:

‘No, I am not sure I am ready for that yet. The time I think I would like to do that is if I come across some challenges.’ NHS01int1

The reasons given by most are the lack of need; however, a few participants never accessed any support as they were never offered any opportunity to do so:

I don’t think I was ever offered any. I think I was told the name of the cancer nurse. They asked if I wanted to speak with somebody, somebody local, and I think I spoke with her once about either RAI or the process. It wasn’t Macmillan, I just felt a lot of the time that I didn’t need that. And other people need it more, and if I don’t need it I shouldn’t do it. TC20

For some people, support methods that their health care providers suggested were just not their preferred form of support:

No, the hospital did suggest it, but what they were offering, it was a group thing, so it is not my thing, I sort of, I knew that I needed to lose weight and get healthy, and it was like I shared a body with thyroid cancer, it was taking over me, so I knew that I needed to get healthy and I’m working with a life coach to achieve that, and slowly get me doing things I used to enjoy in the past. TC16

A small number of participants said they do not feel that their condition justifies the support:

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

Another reason why participants did not access any supportive services because they did not feel they could relate to other cancer patients due to their young age and the rare, misunderstood type of cancer.

Sometimes, accessing support was not possible due to COVID:

I would have liked to go to Maggie’s Centre, I would really love to go there. So, I wasn’t able to go there after my RAI because I was radioactive. After that I was just in and out due to corona but I would like it, to attend a class or speak with someone. So, I

will probably give it a go. Maybe next time. Apart from that I've been fine. You know everybody had their down days, there are some days I was not even able to get out. TC05

The main support forms were counselling, charity and Facebook groups. The minority of people accessed other forms of support like other health care professionals to support them with physical symptoms or psychologists or GP to support them with psychological symptoms. People may not access support when needed because of a lack of need or not knowing the support is available. One of the reasons not to access group support is that some people think that they may not be able to relate to people with other forms of cancer or older cancer patients.

#### **4.9 Work and finances during and after the treatment for thyroid cancer**

Thyroid cancer treatment can be lengthy, and the treatment can have side effects that can affect the capacity of people to carry on with their daily lives, including work. Having thyroid cancer can mean time off work, making choices about career progression and working life in general. However, some people had positive experiences with work being supportive:

They were extremely supportive, I told them what it was, they couldn't be more supportive. They worked by me, if I said I had to work half a day or start later or finish later they were fantastic. TC15

Apart from supportive managers, people appreciate the support of their work colleagues:

'My direct team was so supportive, my immediate team. We have known each other for a long time'. TC12

The main form of support was their kindness, understanding and interest in their lives. Some participants reported that their workplace did not provide good support during their cancer journey. Most of the time, the issue was with the manager and their attitude (being kind) and flexibility (for example, time off work for appointments, sick leave). However, people who experienced the opposite, like kindness and understanding from their manager, had time off work for appointments without losing their holiday time, assessed their work as being supportive:

I had a manager that didn't think that major surgery was a reason to stay off work. I remember going to work and it was 1 hour drive and before I went to the office I used to sleep for half an hour because I was so tired. TC16

This participant had mixed feelings about her work's attitude to her treatment. They felt that managers were not very supportive:

Some of my friends from work they did check on me, but not my managers, so I decided that I don't want to work there anymore, so I handed in my notice, and they made me come and work my notice period which I think it was ridiculous, they could just say don't come in we will just pay you. It was still very fresh, I just had RAI, so I didn't know what the point was. So, anyway, I went in and finished my notice period. But I think they just moved on, and I didn't have any support from my manager, I think they were just waiting for me to leave. That was quite upsetting as I worked there for 3.5 years so being treated like that wasn't very nice. TC11

There was another participant who also left her position due to feeling a lack of support.

Moreover, another participant lost her job as she was told she was not fit to work anymore.

Finally, a few participants were self-employed, and the condition and treatment proved to be a factor that affected their ability to work:

And in the hospital, I was just on 20 tablets during those 2 weeks. I felt like a complete mess. It really, really hit me hard. I was a care worker, I came out of it because I wanted to go somewhere else but diagnosis stopped everything. I always worked since being very young. TC17

The cancer diagnosis impacted career opportunities for a few participants. For example, the participant below had to make the difficult decision not to apply for a promotion at work due to tiredness and feeling that they may struggle with the academic part of a new role :

I was planning to apply for a promotion, and it was the perfect job, timing, but it was full time, and I can't increase my hours. I turned it down because of my situation. (...) And a career potential, I would have been able to do so much. And this prompted me to do a referral to the chronic fatigue service. Because now it was affecting decisions based on how tired I am. And it was a wasted opportunity, and I don't trust my brain, I did a lot of academic stuff before but I am not sure if I could manage now, also not sure about a clinical role, in research it is prescriptive. But in a clinical environment you have to make quick decisions. So, it is limiting my options. TC12

Another person also admitted to struggling with the cognitive aspect of work after the treatment. They made many mistakes at work, had significant gaps in memory and could not be efficient at work anymore.

A small number of participants had to go on early retirement. One participant said it was due to the inability to talk a lot anymore. For a few others, having thyroid cancer meant significant changes to their current role:

I had to have changes to my role, as my role was quite physical, in direct contact with people that just came off the street and they have all sort of needs. So, in my new role I was looking after people that are already in the system, independently living. Before, in direct access I had to do a lot of running around, which I cannot do now, because of problems with my neck and shoulder I have to be more careful. TC10

Also, full-time students had to adjust the trajectory and length of their studies. Thyroid cancer can put a strain on work and study. Sometimes the effect is more psychological, like having increased anxiety related to employment. Some people make changes to their work life due to their experiences. They planned to find an easier part-time job and to spend time enjoying life:

I just actually handed my notice in today, but I wanted to do that for a while, especially with the COVID situation I wanted to see where I am in life, and I am in a situation that my mortgage is paid off, so I don't need a job that pays me a lot of money (...). I am not sure how things will become if it gets too worse in the future, but this is something I'd rather not know until it happens, I couldn't spend my time worried about it and it may never even happen. TC16

The majority of people did not face financial changes due to thyroid cancer. However, quite a few participants had financial challenges and changes due to their diagnosis and treatment:

There was a lot of worry, when after 6 weeks I handed my notice in, that was the point when everything caught up with me, we lost financially overnight, one wage completely, feeling poorly with migraines and psychologically, and to be fair I had a little nervous breakdown. TC22

As seen above, participants appreciated when the workplace was flexible, were fine with time off the appointments and were happy with being off sick for a longer recovery. Disappointments with work were caused by unsupportive management and not understanding time off for appointments, surgery, and recovery. Thyroid cancer can impact working life and career trajectory, and due to patients' financial situation, that can lead to further issues. However, some participants in the study had supportive employment and had not experienced significant changes in their working lives due to thyroid cancer.

#### **4.10 Miscellaneous questions**

##### **4.10.1 The most challenging part**

Participants were asked what the most challenging part of the process was. The answers could be placed in three categories. First, the biggest category included the psychological aspect of the journey. Then the second category was life after treatment, and the third was physical aspect.

##### **Psychological aspects of the cancer journey**

Most participants said that diagnosis and being told they have cancer was the most challenging part of the journey. Participants said the hardest was when their mental health decreased. They had difficulty coming to terms with the diagnosis, their young age when getting diagnosed, the first weeks after diagnosis, thinking about cancer and hearing about it everywhere, including on

radio and TV. One participant said that the initial shock of the diagnosis was the most challenging part of the journey:

I would think probably the diagnosis, I think it would be better if not everybody that I met said that everything is ok. Everybody was saying oh it is very rare, 90% of cases are benign. I wasn't prepared. I guess that take a little while to get the head around. It is a shock. (...)I just wanted to be well again so I guess the diagnosis was the worst. TC20

Being unprepared due to getting so much reassurance. For this participant, not knowing where the primary cancer was, was very difficult:

The hardest part was not knowing what my future was between the operation and (doctor's name) coming to see me. And that was the bit when you are lying in bed thinking how long I've got. That was the hard bit. (...) They could have said you have a bowel cancer, and you have 3 months. You know, but they came back and said you have thyroid cancer and it is treatable, so (...) NHS01int1

For many participants waiting for diagnosis was very difficult. Not knowing if they have cancer or not was very distressing and stressful, and for participant NHS03, it took a few months before getting their diagnosis confirmed. Also, after diagnosis, waiting for treatment was also difficult. One participant said the most difficult part is their loss of trust in the NHS.

But still, I can't trust them at all. Which I recognise is not a healthy place to be. It is not anger as such it is more distrust, when I go for appointments. It is not that I think my cancer is going to come back, it is I don't trust them to get this right. (Interviewer: 'must be hard as you will be monitored'), yes, when people say I am fine, I am like check it again. I understand it must be quite hard from the doctor's point of view, a doctor doesn't want a patient to say check it again. You know. I've spent so long misdiagnosed, I think it is really hard for people who were misdiagnosed to trust. TC07

For the above participant, the lack of trust is causing stress and anxiety. It can be difficult as thyroid cancer survivors are monitored frequently for the rest of their lives, so contact with the health care system will be ongoing. Several participants stated that the psychological aspect of the process is the most challenging. For example, fear, anxiety and other psychological symptoms were the hardest part of the journey:

'The first few weeks after diagnosis, you just feel like you are living in a high state of panic all of the time.' TC14

One participant described that as they are already 'a worrier', it caused more anxiety to deal with thyroid cancer. Another participant stated that the treatment's fear of recurrence is the most difficult part:

I think the worry that it may come back is the big one, because you have so many tests all the time. (...) some people say oh it is thyroid cancer, you will be fine, oh it's

cancer-like, it is not a cancer. And I think that is very unfair, because it still kills people. And it had a big impact on my life. TC10

This participant had a friend who had a recurrence and died of thyroid cancer eight years after the initial operation. This experience made the participant worried about this possibility, although health care providers were reassuring. The recurrence is not common, but it is possible. As in the case of this participant, especially with their experience with their friend, it can be a source of anxiety moving forward. Isolation during RAI treatment was the most challenging part of the journey for one participant, especially due to the food quality and boredom.

### **Life after the treatment is completed**

The second theme that emerged from the answers to the question of what was the most challenging is issues related to life after treatment. Although participants must have lifelong follow-ups, most take medication for the rest of their lives. Also, some still have some symptoms:

I don't know, the difficult bit, the treatment, I mean it is coming to terms that some symptoms, they are always going to be there, I've lost my thyroid so I am going to be on medication for life, hopefully I will be able to reduce my calcium but not yet. And I think the feeling that your body has let you down, it is like, kind of, I am not healthy anymore, I am getting better at it, I can still do plenty of stuff, I can still walk and exercise and things, but it did take me time to start thinking like that, more positive frame of mind rather than negative. TC01int3

For several participants, issues related to hormone replacement therapy are the most challenging:

The most difficult time was the later time, adjusting to levothyroxine, I keep thinking I am getting old, but I am only 63 but I am slower, and I try to keep doing lots of things, I try to do Pilates and tai chi and lots of things, obviously I can't at the moment (lockdown) but I try to keep very active, but I get very tired, and have days when I am sort of not good for anything really. TC08

Sometimes it takes a while to get the hormone levels to optimum and reach a hormonal balance. During that period, people may have problems with thyroid hormones and calcium. In addition, it can give many side effects, especially tiredness.

### **Physical pain and recovery after the surgery**

A few participants stated that recovery after surgery was the most difficult for them:

I would say the most difficult part was the recovery, I just feel like there was no support given. I think when you first get a diagnosis, they are so supportive, they tell you everything that is happening and they keep you informed, and then when the treatment finishes you are almost like thrown out, everything stops, and you are left to deal with it on your own. There is like a space for improvement there, because it was very difficult to recover from the surgery and trying to go back to normal life. Like, my body doesn't feel the same like before treatment and that is normal because my body did change but I would say probably that was the most difficult. TC11

The three main areas people found the most challenging in their thyroid cancer journey were psychological aspects, lifelong disease management and physical recovery from the surgery.

#### **4.10.2 Sources of encouragement for participants**

The second miscellaneous question that participants were asked was what was the most helpful/encouraging for them during their thyroid cancer journey. The answers were grouped in three themes, NHS care, thyroid cancer characteristics and other encouraging factors.

##### **NHS Care**

For the majority of participants, the biggest encouragement is the trust and professionalism of their care team and the treatment that they had:

I mean, obviously the hospital they are doing a brilliant job. If you have any questions, concerns, you have their number, you always know what is going on, you never know in great detail but you know what is going to happen. And the encouragement is that I think for me now, knowing that I am going to be ok, I am able to move on. Got cancer this year, got rid of cancer this year. That is how I am looking at it now. TC17int3

Also, having a specialist nurse is highly regarded as very encouraging and helpful:

I am so grateful that we have the NHS that managed it so well, I get encouragement from the fact that I have TCNS. I know that they don't have that in other parts of the country. TCNS will answer my email almost immediately which is just amazing, I know if there is a major issue I know that she would offer support, so I am really grateful for that yes. TC08

The main reason finding a specialist nurse was so helpful was the access to a key person who could answer all questions. For another participant, Macmillan services were the most encouraging, as well as the main doctor as well as thyroid cancer online community:

For me the Macmillan nurse was really good, my consultant was fantastic, he would answer all the questions and I was always a person that had a lot of questions. I think I joined the Macmillan online community to contact people that had the same treatment, the same surgery. I think that really helped the most. To speak with people that can empathise with how I am feeling, I found it very helpful. You can join, there is one

dedicated to thyroid cancer. I mean there is a couple of people that I email with and chat, but I've never actually seen face to face. TC10

Successful treatment gave people encouragement. This participant also found encouragement in low recurrence rates:

I would say, from a medical point of view I took encouragement from the fact that the treatment was successful, when I had my follow up, the treatment drags for a long time, because of the cyst. (...) So that was hard in that sense, but I took encouragement from the fact that the treatment was successful and that recurrence rates are low, but I don't really know if it will come back. TC11

Another major aspect that participants found encouraging is good long-term monitoring that will enable early discovery of any other thyroid malignancy. In addition, it gave the participant the knowledge and reassurance that if cancer returns in the future, it will be quickly discovered and managed.

### **Thyroid cancer characteristics**

Many people found encouragement in knowing statistical information about thyroid cancer. It has low mortality and recurrence rates, and most people recover very well from it:

The most encouragement is from the fact that it is one of the most treatable cancers, and that the long-term prognosis is usually good. It is a high cure rate. There are many people alive today, continue living ordinary lives, after having had the treatment. That is what encourages me. (...) NHS03int2

### **Other encouraging factors**

It is very challenging to learn that one has cancer. Coming to terms with having had cancer and coping proved to be encouraging for people:

I don't know, I guess at the moment I just came to terms with it now, I accepted it is there, it is something I have to deal with, I am very fortunate that I have a great relationship with my husband, and I have a lot of good things in my life, I've learned a lot of self-compassion, which was very important. Now every time I need to have a scan or appointment I get very anxious in case it doesn't go away but every day I just try to come to terms with it. TC09

Many people found their resilience and strength very encouraging:

'I realised that I am actually a really resilient person, wow, I can go through all of this, and I am still ok, I have impressed myself.' TC09

A few people mentioned that support from their loved ones as well as friends and charities was very encouraging:

Another thing that was encouraging was support from friends and family and charity. And my partner was great, it definitely affected our relationship because he had like a carer role but as soon as I felt better it came back to normal and our relationship strengthened, I know I can rely on him in any situation. Relationships can break down in situations like, some people can't cope, it is too much. I am lucky that I have not been in that situation. TC11

Participants also mentioned support from Facebook group friends, feeling normal again and having positive people around.

As seen above, participants found levels of NHS care, characteristics of thyroid cancer and support they were given by friends, family and charity the most encouraging.

#### **4.11 Results of content analysis**

##### **Content Analysis results: Factors affecting wellbeing among patients with Thyroid cancer**

Content analysis was used in order to determine how different common factors were. It is important to note that the factors were only identified when mentioned by participants. Thus, looking at the numbers in the table at opposing factors, the numbers do not always add up. For example, out of 25 participants, 19 said they had fatigue. However, four participants stated they had no significant fatigue, not five. The nature of qualitative interviewing is that the same questions are not asked of every person because respondents are allowed to direct the interview to the topics that interest them. Therefore, the researcher does not know whether one respondent experienced fatigue or not because they did not mention it. It most likely means they did not experience it, but it would be wrong to make this assumption.

##### **Common factors affecting wellbeing among people with thyroid cancer**

The most common positive factors, universal to all participants in the study, include supportive family and friends, satisfaction with scars, being well informed, having a supportive partner, receiving support from HCPs and charity, having positive surgery, and coping well. Conversely, the most common negative factors include long-term physical symptoms, psychological symptoms, fatigue, and postoperative symptoms.

**Table 4.3 Negative and Positive factors in all participants.** Number of participants: 25

<b>POSITIVE</b>		<b>NEGATIVE</b>	
<b>family supportive</b>	<b>23</b>	<b>long-term physical symptoms</b>	<b>21</b>
<b>happy with scar</b>	<b>23</b>	<b>other psychological symptoms</b>	<b>19</b>
<b>well informed</b>	<b>19</b>	<b>fatigue</b>	<b>19</b>
<b>partner supportive</b>	<b>19</b>	<b>post op symptom</b>	<b>17</b>
<b>HCP supportive</b>	<b>19</b>	<b>distressed waiting</b>	<b>13</b>
<b>positive experience of surgery</b>	<b>18</b>	<b>negative recovery</b>	<b>13</b>
<b>happy with monitoring</b>	<b>17</b>	work affected	12
<b>coping well</b>	<b>16</b>	not coping well	11
<b>friends supportive</b>	<b>15</b>	some NHS complains	10
<b>accessed charity support</b>	<b>15</b>	finances affected	10
<b>positive recovery</b>	<b>13</b>	COVID negative	9
<b>work not affected or very supportive</b>	<b>13</b>	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
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	7	family not supportive	2
changes in fitness-positive	4	partner	1
		partner not supportive	1 not supportive, 4 singles

### **Combined results of phenomenological analysis and content analysis**

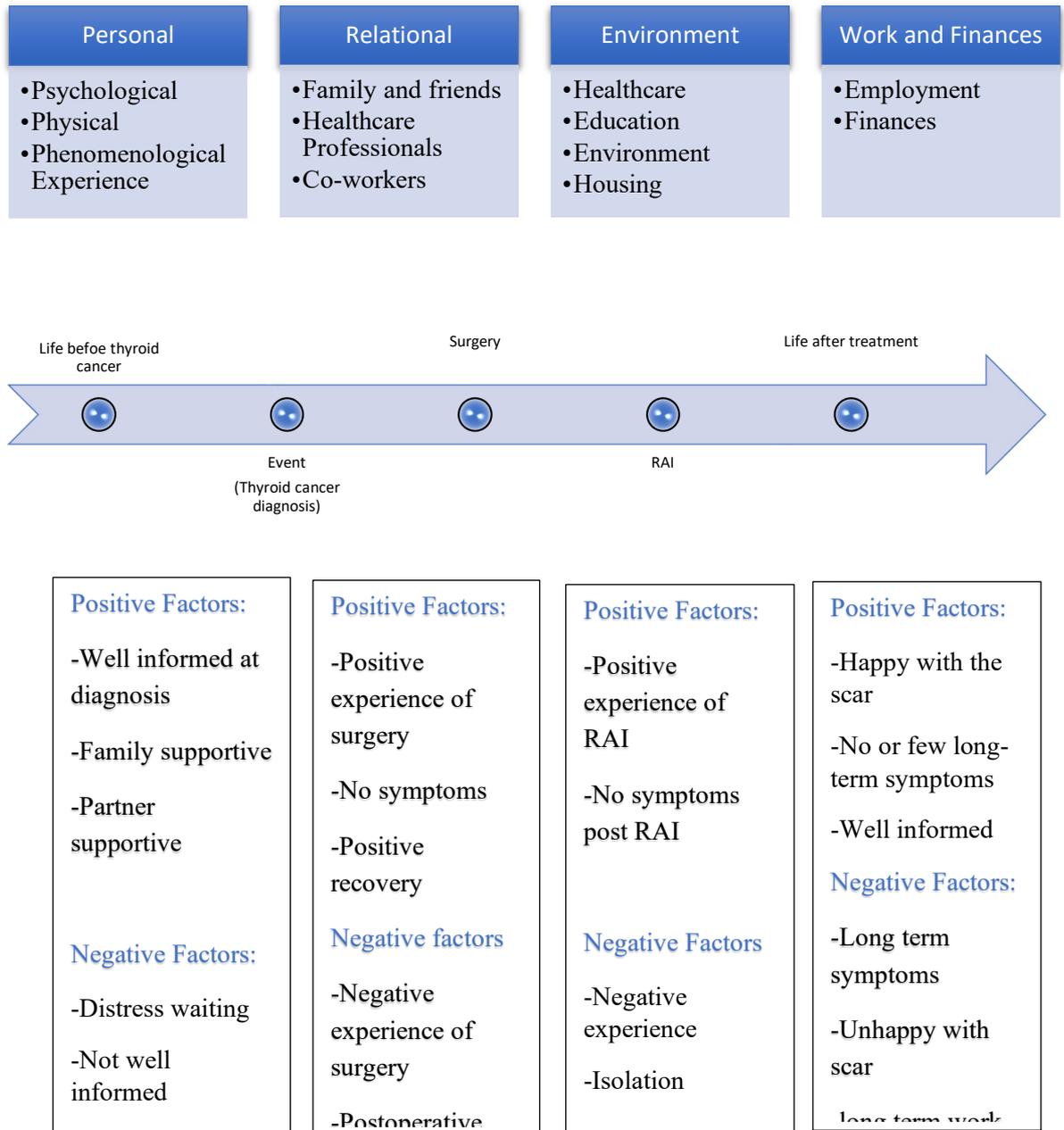
Looking at the combined results of content analysis and descriptive phenomenological analysis, four areas that stood out as most important for the study participants were identified:

1. There are gaps in information provision, especially in psychological effects and support, long-term symptoms, and levothyroxine.
2. The positive attitude of staff is essential in creating a positive experience, and negative interactions impact the experience of cancer negatively.
3. Physical symptoms from treatment and during recovery disturb the participants' daily lives. In addition, some of the side effects last for a long time.
4. Thyroid cancer diagnosis treatment and follow-up generate a lot of anxiety and fear that can last years after the treatment is completed.

## **Factors affecting lived experience**

A framework of time-changing factors was designed (see Figure 4.1). 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, side effects, or many months and years later, for example, long-term symptoms or financial strain. Other factors may be present throughout the experience, like fear of recurrence, in different intensities. The framework can help describe the complexity of changes in significant factors that affect people with thyroid cancer.

**Figure 4.1 Framework for Factors Affective Lived Experiences**



#### 4.12 Chapter Summary

This chapter presented results from descriptive phenomenological analysis and content analysis. Most study 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. Before the diagnosis, most participants had a normal, physically active, and busy lifestyle filled with work, hobbies, travel and family.

An investigation into thyroid cancer starts after discovering a lump in the neck area. Sometimes, the lump could be palpated. Other times, it could be seen in the mirror. The process stages are filled with worry about the possible diagnosis, exaggerated by the prolonged waiting. Factors that impact the experience include the attitude of health care staff. The testimonies of study participants suggest that most staff they came across were supportive, friendly, and reassuring. However, few participants met with indifference and an uncaring attitude. This experience stood out for them and stayed in their memory as part of the negative aspect of their thyroid cancer journey.

When the disease is confirmed, sometimes already following the surgery, it brings many negative emotions, including shock, distress, worry, fear and embarrassment. The news of thyroid cancer diagnosis disrupts people's busy lives and affects their lives for a long time. Most people never heard about thyroid cancer before. Therefore, it is very important to have family present when receiving a diagnosis. When the diagnosis was confirmed, participants were faced with even more waiting, which also caused further worry and fear of the surgery and the longer-term impact on their life and health. Also, worry about the scar significantly impacted some of the participants. However, some participants felt well prepared and reassured and had positive feelings regarding future treatment.

Factors that contribute to the positive experience of surgery are feeling physical well after the surgery and compassionate care. The key to reassuring the participants was the kindness and friendliness of the staff, good level of clinical medicine and nursing care, as well as confidence in the expertise of the team. The negative experience of surgery is related to high levels of pain and discomfort, negative experiences of care, lack of adequate support and a disturbing environment. Most people found recovery challenging. The most common complaints regarding the surgery were tiredness, pain, swelling, voice problems and swallowing discomfort. In the study, a second operation did not seem to significantly impact people as most knew what to expect and had a better experience than with the first surgery. Some, of course, were distressed to be told they needed further surgery. However, most participants seemed to cope very well with the second surgery. Only two study participants had a single hemithyroidectomy as their treatment without needing a second operation. Thyroid surgery is an important event that affects the lives of people with thyroid cancer. It may come with physical and psychological symptoms, long-term symptoms and complications that can affect and disturb people's everyday lives.

RAI treatment can be a positive experience for many participants. However, some participants thought it very challenging, especially concerning loneliness and isolation. Other issues identified by participants were feeling forgotten, issues with hospital food and boredom. In

addition, while most people did not experience significant physical symptoms during or following treatment, some participants experienced pain in their saliva glands, tiredness, and temporary taste alterations.

Following the treatment, many long-term physical symptoms can impact people's lives. Fatigue, neck pain and tightness, voice problems, permanent swelling heart palpitations are among the symptoms mentioned by the study participants. Most participants were cleared of the disease when the study was conducted. However, some participants had metastasis of their thyroid cancer. Naturally, this provides even more worry and anxiety for participants. While other participants were engaged in moving on from the disease, thyroid cancer is still a big part of their lives for people with metastasis and persistent disease.

The covid pandemic proved to be an additional challenge to many participants. It created more worry and distress. Especially patients that went through treatment during the pandemic faced many challenges. However, participants felt reassured when the statement was released by BTCT charity that there is no evidence that patients with Thyroid cancer are at increased risk for Covid or its complications when compared with the general population.

Most participants in the study were happy with managing their disease through the healthcare system. However, there were some complaints regarding waiting times between treatments, the treatment being disjointed due to the involvement of many clinical teams, and operations being wrongly conducted, cancelled surgeries and appointments.

Information provision is a topic often mentioned by the study participants, and some gaps in information provision were identified. Some participants felt they were prepared for some aspects but not for other aspects of the process. For example, a common complaint was the lack of information about taking levothyroxine. Moreover, some participants said they found information that they provided too general and not thyroid cancer-specific. Other participants mentioned that they were not prepared to deal with stiffness, physiotherapy and exercises, how unwell they would feel after the operation, swallowing after the operation, and the length of follow-ups. As seen above, the three major gaps in information provision were the physical aspects following surgery, including long-term physical symptoms, psychological aspects of the cancer journey, and levothyroxine information.

The psychological health of patients with thyroid cancer was significantly affected. Most symptoms related to psychological health improved over time. Anxiety symptoms were the most common. Participants of this study worried about recurrence, metastasis, other unrelated

cancers and long-term physical symptoms. When relevant, participants were worried about their future fertility. Follow-up appointments and the need to be monitored for the rest of their lives can be both reassuring and worrying for people. Following the treatment, participants described the process of accepting that the thyroid cancer experience is part of their lives.

Moreover, participants' accounts show the need to move on from this. Many described processes of transformation. Three main areas of positive transformation following the treatment for thyroid cancer were a more positive and appreciative attitude toward life and other people, adapting hellfire lifestyle habits to improve health and actively helping others through fundraising, volunteering, and participating in thyroid cancer-related research.

Participants sought and utilised various support tools to help them get through the disease and treatment. The main form of support was counselling, charity and Facebook groups. A minority of people accessed other forms of support like other health care professionals to support them with physical symptoms or a psychologist or GP to support them with psychological symptoms. People may not access support when needed because of a lack of need or not knowing that the support is available. One of the reasons not to access group support is that some people think that they may not be able to relate to people with other forms of cancer or older cancer patients.

Work and finances are other areas heavily affected by the disease and treatment. Participants appreciated when the workplace was flexible, were fine with time off the appointments and were happy with being off sick for longer recovery time. Disappointments with work were caused by unsupportive management, them not understanding about time off for appointments and time off for surgery and recovery. Thyroid cancer can impact working life and career trajectory due to patients' financial situation, which can lead to further issues. However, some participants in the study had supportive employment and had not experienced significant changes in their working lives due to thyroid cancer.

Thyroid cancer is a disease that can change people's lives for some time. It affects people's physical health, mental health, relationship with others, finances, and employment.

In the next chapter, the main finding is discussed and compared to what is already known on the literature.

## **Chapter 5 Discussion**

This chapter discusses the key research findings and their relationship to previously published research.

### **5.1 Research Aim of the study**

The study aimed to explore the lived experiences of adults diagnosed with well-differentiated thyroid carcinoma. The first objective was to use qualitative methods to explore the experiences of thyroid cancer patients – from diagnosis to recovery – from the patient's perspective. The second objective was to explore the impact of hospital care and treatment. The third was to establish what factors affect the lived experience in positive and negative way. And finally, to make recommendations for improvements to practice in the care of thyroid cancer patients.

### **5.2 Discussion of main findings**

#### **5.2.1 Experience with hospital care and treatment**

There is very little published information on patients' experience of treatment for thyroid cancer. Most studies concentrated on measuring the effects of treatment on quality of life. Thus, this is one of the main areas of original contribution to knowledge. In this chapter, the author draws on studies specific to thyroid cancer patients when they were available but also draws on wider studies (for example, of patients with other cancers) where that are relevant to the findings.

##### **5.2.1.1 Experience of surgery**

###### **Experience of care**

Most participants had very positive experiences with their surgery. The majority of patients experienced excellent care in the hospital. The positive experience mainly relates to care provided by the hospital care team and having positive interactions. However, it is important to note here that a few participants in the study expressed that they did not feel treated like individuals during some parts of the treatment. One participant stated they felt rushed during surgery and felt like being on a conveyor belt. Another participant stated that they felt like just a

number. It is in our human nature that we want to be treated as individuals. This has been addressed previously in the literature. Patients want to be seen as unique and treated like a number or another person with this condition (Browall *et al.*, 2013). Moreover, trust is essential for participants and can affect their quality of life (Browall *et al.*, 2013). Mistrust of the NHS system affected a few participants in the study. Although most patients were very appreciative of the care received, a few participants had negative care experiences, and, in their subjective opinion, this impacted their experience significantly. For example, for one participant, the experience of the NHS during their thyroid cancer treatment confirmed their decision not to have a child. Another patient is doubtful they even had cancer and is convinced they should not have had the surgery. The notion of distrust in the UK's healthcare system is in line with previous research, such as the study by (Hedman, Strang, *et al.*, 2017). Participants in that study were apprehensive about recurrence being missed, which was also reported by a small number of the study participants.

### **Side effects of surgery**

There are many similarities between the literature and the results from this study regarding the side effects of surgery for thyroid cancer. In the current study, 17 participants complained specifically about their postoperative symptoms. Most thyroid cancer patients reported a variety of physical problems in other studies (Buchmann *et al.*, 2015; Hedman, Djärv, *et al.*, 2017). Based on the researcher's conversations with patients, it is evident that physical side effects negatively impact patients' lives. It is supported by a previous scholar who concluded that patients that reported major symptoms had significantly lowered health-related quality of life compared with people without major physical symptoms (Hedman, Djärv, *et al.*, 2017). Most present study participants found recovery challenging with postoperative and long-term symptoms. The most common postoperative symptoms include pain, stiffness, tiredness, voice problems, swelling, and swallowing issues (Husson *et al.*, 2011; Choi *et al.*, 2014; Vega-Vázquez *et al.*, 2015; Rogers *et al.*, 2017). All reported side effects are well documented in the literature and are experienced by all or almost all patients to some extent. Long-term and severe physical effects appeared to outweigh many other positive factors in their impact on wellbeing.

The next most common group of symptoms after thyroidectomy that affects people and their lives are those related to scars (Huang *et al.*, 2004; Easley, Miedema and Robinson, 2013; Choi *et al.*, 2014; Gallop *et al.*, 2015). Most participants in the present study explained that their scar has healed well and is not impacting their life. Even after two surgeries and staples, the scar can heal neatly. This is supported by the literature, side effects and symptoms are present in 64 patients (66.0%), including pruritus (itchy skin) (n=37, 38.1%), tightening (n=29, 29.9%), pain

(n=12, 12.4%), and burning sensation (n=3, 3.1%) (Choi *et al.*, 2014). Most people in the present study were advised to massage the scar to promote healing, decrease tightness, and minimize scarring. However, a few participants felt they could have received more advice regarding their wound care and scar. However, for most participants in the study, it was not physical symptoms related to the scar that was problematic. It was more related to the psychological effects of the scar and body image issues. Interestingly, all male participants were quite satisfied with the look of their scars. However, for some female participants, the scar proved to be a distressing topic. Body image issues are possible because of scarring (Easley, Miedema and Robinson, 2013).

### **Complications**

Some negative surgery experiences for study participants were due to care and physical factors. Physical factors can occur when surgery is performed well and there are no complications. However, complications can occur and may be linked with the quality of surgery. One research study and one literature review suggest that the quality of surgery impacts overall experience (Dimov, 2013; Bãrbuș *et al.*, 2017), especially if low-quality surgery leads to side effects or complications (Dimov, 2013). Eight participants (32%) in the present study experienced postoperative complications. The most common complication was swelling that needed to be drained. Other complications included wound infection, calcium deficiency issues, hypertension, shoulder nerve damage, seizure caused by deficient calcium, and permanent face swelling. One participant had to stay in the hospital for two weeks following surgery due to complications (problems with calcium). Another became septic due to a severe wound infection. Sepsis is a serious and life-threatening situation (Singer *et al.*, 2016). It is a surprisingly high number of complications in a sample of 25 people.

On the contrary, the literature reports relatively low complication rates of 3.28% across all thyroidectomies (Fassas *et al.*, 2021). Moreover, two participants of this study experienced significant mistakes in their surgeries. They both had the wrong side of the thyroid removed. It is rarely reported in the literature (Dionigi *et al.*, 2021). As this study sampling method included self-selection, people who experienced severe complications and mistakes may have been more likely to participate in a study about the wellbeing of people with thyroid cancer. The self-selection bias is discussed further in Limitations of the Study on page 183.

#### **5.2.1.2 Experience of Radioactive iodine treatment**

Although RAI is not a particularly invasive intervention, it proved to be a source of worry for most, if not all, participants. Their main reasons for anxiety were lack of familiarity, previous

knowledge about the procedure, and fear of any side effects. These results are supported by (Gallop *et al.*, 2015) and (Sawka *et al.*, 2009), whose study participants also reported worrying about RAI treatment. When participants in the present study experienced RAI treatment, some felt that worrying about RAI treatment was worse than the actual experience. A few people expressed that RAI treatment felt very anticlimactic. However, it has been reported in the literature that RAI treatment participants report lower quality of life (Haraj *et al.*, 2019; Gkatzia *et al.*, 2021). It could be due to physical side effects and negative experiences of RAI. Factors that mostly created negative experiences during RAI among participants of the present study were factors related to isolation, going to the hospital alone (during COVID), confinement, being bored, the suite being very small, being served bad hospital food, food being served very late or not at all, and feeling is forgotten about. Isolation is a factor that was raised in previous literature (Easley, Miedema and Robinson, 2013; Anh *et al.*, 2016). It often psychologically affects participants as they are isolated from family, friends and the health care team. They sometimes must stay away from their children even after leaving the hospital, intensifying the distress. The results of the present study reconfirm the opinion that emotional and physical factors related to RAI treatment affect the overall experience of treatment (Husson *et al.*, 2011; Anh *et al.*, 2016; Haraj *et al.*, 2019; Gkatzia *et al.*, 2021). The present study results provide more insights into why this is the reason and that isolation and physical side effects are not the only factors affecting the experience.

While some people from the present study did not experience any symptoms related to RAI, if present, symptoms commonly reported were taste alterations, sore saliva glands and tiredness. Some of these symptoms were quite severe, especially fatigue and painful salivary glands, which can be uncomfortable. According to (Rogers *et al.*, 2017), most participants who experienced side effects after RAI had short-lived side effects. In their study, 9 participants (out of 15) reported at least one side effect from RAI, for example, nausea, painful salivary gland swelling, changes in taste, sore throat, rash, hair thinning, or menstrual changes. Common symptoms reported in other studies include impairment of salivary function, taste disturbance, and sialadenitis (infection of salivary glands) (Schultz, Stava and Vassilopoulou-Sellin, 2003; Gallop *et al.*, 2015; Hedman, Djärv, *et al.*, 2017). No participants in the present study reported any serious, long-lasting symptoms that could be symptoms related to RAI. However, one participant is unsure whether their taste returned to 100% or slightly below that. Also, another participant feels occasional tightness in their salivary glands, but only when dehydrated. Hence the study results is in line with previous literature.

## **Low-iodine diet**

Previous literature suggested confusion regarding the diet and its specifics (Herbert *et al.*, 2020). Participants of the study had mixed opinions about the diet. Some did not mind it, while others found it challenging to get used to and plan their meals. However, some people strongly believe that diet is an essential part of the treatment, and this is supported by literature (Herbert *et al.*, 2020).

## **Long-lasting physical symptoms**

Although most side effects of the treatment were short-lived, some symptoms lasted longer. The most common long-lasting symptoms reported by this study participants included fatigue and neck tightness. Moreover, 21 out of 25 participants reported experiencing long-term symptoms. Thus, only four people had no long-term physical symptoms. In Gómez *et al.* (2010) study, 45% of participants had no significant symptoms related to thyroid cancer treatment. Here, self-selection bias could also play a part, and people with long-lasting symptoms might be more likely to participate in a study regarding the experience of thyroid cancer and treatment. Also, sometimes the symptoms can be minimal, such as slight neck tightness in the neck area. In the literature, thyroid cancer survivors are likely to report long-term side effects like memory problems (Schultz, Stava and Vassilopoulou-Sellin, 2003; Easley, Miedema and Robinson, 2013), headaches and psychological problems (Schultz, Stava and Vassilopoulou-Sellin, 2003; Hedman, Strang, *et al.*, 2017). Moreover, although there were no reports of headaches and specific memory problems among this study participants, psychological symptoms were widespread. However, a few participants reported a brain fog phenomenon and difficulties concentrating and performing.

## *Fatigue*

The major complaint among patients of this study is long-term tiredness and fatigue, which is extremely common. Participants understand that their tiredness is most likely due to a lack of a thyroid gland. The severity varies. In some people, it is so severe that it can impact career choices, job security, financial future, and other areas of life. All these study participants experienced fatigue at some point during their treatment and recovery. However, it was quite severe for 19 participants. The results are in line with previous research on the topic. Fatigue is one of the most common physical side effects reported by patients with thyroid cancer (Huang *et al.*, 2004; Roberts, Lepore and Urken, 2008; Gómez *et al.*, 2010; Lee *et al.*, 2010; Roerink *et al.*, 2013; Duan *et al.*, 2015; Gallop *et al.*, 2015; McIntyre *et al.*, 2015; Anh *et al.*, 2016; Alhashemi *et al.*, 2017; Rogers *et al.*, 2017). In addition, a figure can affect mental health and

quality of life (Huang *et al.*, 2004; Rogers *et al.*, 2017). Participants in this study confirmed this; their main complaint regarding wellbeing was often fatigue. For example, one participant had to nap in a car park after commuting one hour to work. Another participant mentioned that they could not play with their children due to tiredness. Also, daily activities like walking a dog proved to be too taxing for one participant, even ten months after treatment. However, the last participant had persistent disease and underwent chemotherapy treatment, which could also explain severe tiredness. The stories from study participants provide more context to previous literature findings that were usually the result of a cross-sectional questionnaire showing that tiredness was one of the complaints of thyroid cancer patients.

### *Voice problems*

Most participants of the study have no long-term voice problems. Even if there was some croakiness initially, it improved in time. However, a few participants have long-lasting problems with their voice, and one has permanent vocal cord palsy (from cancer, not the surgery), making talking difficult and taxing. It is well documented that voice changes include, for example, hoarseness (Easley, Miedema and Robinson, 2013; Hedman, Djärv, *et al.*, 2017) and paralysis (Easley, Miedema and Robinson, 2013; Lubitz *et al.*, 2017). Moreover, although minor voice problems are not very important for most people (Singer *et al.*, 2016), voice changes are highly associated with decreased quality of life. In addition, a recent study confirms that voice abnormalities following surgery can be very prevalent (Kovatch *et al.*, 2019). In the present study, people who were especially worried about their voice quality were people involved with singing and professionals worried about how their voice would affect how they present themselves at work.

### *Hormonal therapy*

Due to having had their thyroid removed, patients with thyroid cancer require lifelong thyroid hormone replacement therapy. However, establishing the correct dose may take some time, and people may experience temporary hypothyroidism (Laura *et al.*, 2019). In the present study, some people were still having their dose altered and had not reached the optimal dose. However, a few participants said they are on their optimal dosage now and feeling much better than before, especially regarding fatigue and sleep problems. Among the symptoms mentioned by participants were sleep problems, fatigue, weight gain, heart palpitations, cold or hot flushes, and sweating. All of those problems can be quite disturbing, especially sleep problems, as they are prevalent and can affect other aspects of life like tiredness and productivity.

These results are supported by literature as being common symptoms of thyroid hormone dysregulation (Schultz, Stava and Vassilopoulou-Sellin, 2003; Tagay *et al.*, 2006; Roberts, Lepore and Urken, 2008; Steel, Schmidt and Shultz, 2008; Pelttari *et al.*, 2009; Roerink *et al.*, 2013; Rubic *et al.*, 2014; Aschebrook-Kilfoy *et al.*, 2015; Duan *et al.*, 2015; Anh *et al.*, 2016; Applewhite, White, *et al.*, 2016; Singer *et al.*, 2016; Hedman, Djärv, *et al.*, 2017). Moreover, the literature suggests that lifelong therapy may impact HRQoL more than previously anticipated (Kansagra, McCudden and Willis, 2010; de Oliveira Chachamovitz *et al.*, 2013; Edafe *et al.*, 2014; Gamperet *et al.*, 2015). However, serum TSH is not a predictor of impacted quality of life. (Hoftijzer *et al.*, 2008; Laura *et al.*, 2019). Herefore, the author of this thesis suggests that symptoms may be a better indicator of hormonal imbalance than TSH measurements. Looking at the present study's statements and experiences of thyroid cancer patients, it can be concluded that hormone replacement therapy affects the quality of life in situations of hormonal distortion. However, when the dosage is optimal, the symptoms should decrease, improving participants' quality of life and daily lives.

### **5.2.2 Information provision**

For all participants in this study, having information was pivotal. Most participants in the study were given sufficient information on diagnosis. Information provided from BTCT and Macmillan specific to thyroid cancer was especially appreciated. It is essential as it is well reported in the literature that information provision is one of the major factors impacting the experience of people with thyroid cancer (Wiener *et al.*, 2019). However, some felt they received information far too late into the process, while others stated that they had not received good information. For example, a few participants received information about general thyroidectomy that did not address their specific concerns and seemed inappropriate. It seems that having thyroid-specific information is very important. According to (Husson *et al.*, 2013) and (Wiener *et al.*, 2019), a good level of disease-specific information improves disease perception; thus, it is essential to give patients tailored information.

Some participants in the present study stated that being well informed was their coping mechanism, and being confused regarding treatment, not remembering information that the doctor gave and feeling like it was not thyroid-specific was very worrying for them. Thus, the study results align with other authors who concluded that informed patients cope better than uninformed patients (Duan *et al.*, 2015).

Most people in the present study received their initial information from the doctor delivering their diagnosis or a Thyroid Cancer Nurse Specialist. Almost all patients received information packs from their care team at the hospital. In general, most participants in this study (19-76%)

were satisfied with the information provided, similar to findings from other studies (Roberts, Lepore and Urken, 2008). However, one study reported that 63% of participants received no written thyroid cancer-specific information (Banach *et al.*, 2013). Present study participants reported some important gaps in information provision. Three major 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). There are still many gaps in information provision and unmet information needs.

Most patients who participated in this study reported that a nurse specialist was and still is the first point of contact. Some people who did not have a thyroid cancer nurse could ring a McMillan nurse or ENT nurse in their hospital and contact their consultant via their secretary. They also reported that they received much information from their doctor. The literature supports it. The main information source for patients is healthcare professionals, mainly doctors (Roberts, Lepore and Urken, 2008; van de Wal *et al.*, 2016). The Internet was rated as less necessary as a source of information by participants in this study which is also supported by literature (van de Wal *et al.*, 2016). However, a few participants mentioned that they were more likely to ask the online thyroid cancer community on a Facebook platform if they had any questions. As discussed in the results section, a small number of study participants felt very confused about whom they needed to call if they had any questions. Not having a key worker was distressing, which is not surprising looking at how multidisciplinary the treatment is.

Moreover, the lack of information also included a lack of information and understanding among health care professionals. Most people in the study were looked after in a general surgical ward and felt that the staff were not very knowledgeable regarding their condition and the care needed. Because thyroid cancer is rare, there is no recognition of the disease among health care professionals and the general public compared to breast cancer. For example, there is much information to help HCPs, inform their care of patients and inform the patients themselves. An illustration of this is that other cancer survivors have an abundance of additional services like CBT therapy, formal psychological support, education, lifestyle interventions, and ongoing research (Grogan, Aschebrook-Kilfoy and Angelos, 2016). It informs both HCPs and patients and impacts their wellbeing. Consequently, it is possible that thyroid cancer survivors do not have the same sense of broad support for their diagnosis and, therefore, do not have as good a QoL.

### **5.2.2.1 Involving patients in decision making**

Decision involvement was not a topic often brought up by participants of the present study. Participants mostly trusted doctors to provide them with a treatment plan. A few participants mentioned that they were given the option to have radiotherapy and decided to have RAI in most cases. However, in retrospect, one participant wished they had been more involved in decision-making. They said they were just told what treatment they would have, and no options were given. Once the treatment had finished, the participant regretted going ahead with surgery as they believed they should not have had the surgery. No other patients reported regretting any parts of the treatment. (Sawka *et al.*, 2012) confirmed that regretting RAI was low among their study participants. For some people, being included in the decision-making process is more important than others. However, patients should always be aware that they can have more input into the decision if they wish.

### **5.2.3 Psychological effect of thyroid cancer**

#### **Reaction to diagnosis**

Most of the time, during the investigation into thyroid nodules, people were aware that the unlikely outcome might be that they might have thyroid cancer. Some participants were not told about the possibility of cancer and found out after the initial surgery. However, even if they knew this was a possibility for most people, the first reaction to receiving their cancer diagnosis was shock and distress. It has also been reported in the literature (Husson *et al.*, 2013; Anh *et al.*, 2016; Applewhite, James, *et al.*, 2016). Even though all participants in the present study were told about their favourable prognosis, people still experienced significant distress. Some reported thinking about their relatives who had died of cancer and what a difficult experience they had before dying. All participants were told straight away and reassured about their prognosis (if it was possible at that stage), but they concentrated, especially initially, on the fact that they had or had 'cancer'. The word 'cancer' is very fear-inducing (Duan *et al.*, 2015).

#### **Fear of recurrence**

Many participants of this study experienced or still were experiencing (at the interview) fear of recurrence, even when their prognosis is excellent, and they had reassurance from their doctor. The findings of other studies support this. Fear of recurrence is one of the most commonly reported concerns in oncological patients, and it is universal for all cancer types, including thyroid cancer (Roberts, Lepore and Urken, 2008; Aschebrook-Kilfoy *et al.*, 2015; Gallop *et al.*, 2015; Koch-Gallenkamp *et al.*, 2016; Singer *et al.*, 2016; van de Wal *et al.*, 2016; Cohee *et al.*,

2017; Hedman, Strang, *et al.*, 2017; Lubitz *et al.*, 2017; Maria Papaleontiou *et al.*, 2019), especially in young adults (Crist and Grunfeld, 2013; Lane *et al.*, 2019). The participants in the present study were up to 3 years following diagnosis; however, in literature, studies that follow participants for many years from treatment reported that even then, people experience strong fear of recurrence, even as long as 15 years after initial diagnosis (Rogers *et al.*, 2017). The present study participants experienced various levels of fear of recurrence, and although some are trying to move on and not think about it, it can come back when it is time for a follow-up appointment. Some participants stated they get nervous after the visit as they have to wait a few weeks for the blood test results.

### **Anxiety and depression**

Several participants in the present study reported increases in symptoms of anxiety and depression since getting their diagnosis. It is very well documented in the literature regarding cancer in general (Stark and House, 2000; Carlson *et al.*, 2004; Gutkin *et al.*, 2019; Maillet *et al.*, 2019) as well as specifically thyroid cancer (Choi *et al.*, 2019; Dionisi-Vici *et al.*, 2021). The present study's results indicate that anxiety and depression can be linked to thyroid cancer in only some people but in all phases of treatment, which is also supported by another author (Gallop *et al.*, 2015).

Anxiety symptoms mostly improved with time for this study participant, which is also in line with existing evidence (Alfonsson *et al.*, 2016). Many patients expressed no need for extra support related to their anxiety. They could cope with the standard support from health care providers and their social and family circles (Carlson *et al.*, 2004). In the present study, 44% of patients (11) stated they feel no need for support. Thus, quite a substantial number of patients with thyroid cancer cope very well with the challenges of the disease.

Moreover, although the presence of anxiety and depression may be unrelated to thyroid cancer as the prevalence of anxiety in the general population is relatively high (Haller *et al.*, 2014), only one participant in the present study had previously been diagnosed with anxiety and depression. All other patients stated they had an everyday happy life before diagnosis. It is vital to screen thyroid cancer patients for depression as untreated. Underlying depression could affect overall survival in cancer (Onitilo, Nietert and Egede, 2006; Holland and Alici, 2010). Consequently, the pre-existence of anxiety and depression amplifies the risk of adverse psychological challenges during the thyroid cancer journey. It seems not only that thyroid cancer is linked to anxiety and depression, but also that anxiety and depression can negatively impact the quality of life in people with thyroid cancer.

In line with previous studies, present study participants frequently reported worry about future prognosis, future metastasis and getting diagnosed with other cancers (Aschebrook-Kilfoy *et al.*, 2015; Hedman, Djärv, *et al.*, 2017). Many study participants frequently think about their mortality and death, as supported by other studies (Hedman, Strang, *et al.*, 2017; Maria Papaleontiou *et al.*, 2019). One of the reasons for this fear among this study participants was that they read stories on Facebook of people who had that happen to them. Also, they cannot receive reassurance from doctors that this will not happen as it is, of course, possible, although unlikely. Diagnosis treatment and side effects are common sources of fear among participants of the present study and other studies (Sawka *et al.*, 2009; Duan *et al.*, 2015; Maria Papaleontiou *et al.*, 2019). Also, some of this fear is influenced by stories of people who had a very negative treatment experience.

Several participants were worried about their future fertility. The fears mentioned include difficulty getting pregnant and potential risks for the baby. Moreover, fear of problems in becoming a mother was highly correlated with decreased quality of life (Singer *et al.*, 2016; Sodergren *et al.*, 2018). Other sources of fear that came up in the present study that, according to the researcher's current knowledge, have not been previously reported in the literature are difficulty planning future events like holidays or weddings and anxiety related to having to go to follow-up appointments. The literature regarding fear and distress is presented in the literature review.

### **Good cancer**

All participants vigorously agreed that Thyroid Cancer is not a 'good cancer'. Participants said that their particular cancer is highly undermined by society on many levels. They heard the phrase from health care professionals, friends and colleagues. The same phenomenon has been reported in previous literature (Tagay *et al.*, 2006; Sawka *et al.*, 2009; Husson *et al.*, 2011; Costa and Pakenham, 2012; Easley, Miedema and Robinson, 2013; Anh *et al.*, 2016; Randle *et al.*, 2017). The author of this thesis speculates that most people who refer to thyroid cancer as a 'good cancer' likely have genuine intentions. However, instead of making people feel better, it devalues and undermines the challenges and difficulties they are facing, and other scholars support this. The label 'good cancer', often used by media and healthcare professionals, is not reassuring (Sawka *et al.*, 2009).

Looking at results of the present study, it can be observed that a good prognosis and less invasive treatment options can make a small number of participants feel lucky. Nonetheless,

referring to thyroid cancer as a ‘good cancer’ has mostly negative results, provoking feelings like invalidation and confusion. Some participants expanded that they do not think about it as good cancer, they do not want it, it was/is not a positive experience and does not provide them with any benefits or happiness. The author of this thesis, supported by other authors like (Randle *et al.*, 2017), recommends that the term is not used in conversations with patients with thyroid cancer. By stating it is a ‘good cancer’, we impose the meaning of their experience as having good cancer. It is important to let cancer patients make the meaning of their disease. Thus, it can be noticed that there is a dissonance between how healthcare workers and the general public perceive thyroid cancer and how patients see it.

### **Making sense of thyroid cancer**

People in the present study explained that although they are trying to move on with life, there is always that thought at the back of their minds. However, they accept it as a part of their new life. One participant explained that they sometimes allow themselves to feel sad as the ability to feel negative emotions allows the presence of positive ones. One participant said that they learned self-compassion, and it helped them to accept their new reality. Another patient felt grateful when they had a good day and lots of energy. Another one was grateful for their partner and supportive family. Some participants felt that gaining knowledge about their condition was a major part of coping. All the above are attempts to move on with life in their new reality.

Antonovsky’s Sense of Coherence (SoC) theory was first introduced (Antonovsky, 1979, 1987) and is widely used in the literature looking at coping and the meaning of critical life events. What is very important is a person’s perception and comprehension of their situation. For example, a study by (Harrop *et al.*, 2017) looked at meaning and coping for people with advanced lung cancer, drawing on the theory of SoC. They have identified three areas: making sense of and managing one's illness; maintaining daily life and relationships, and confronting the future. Looking at the present study results, people tried to make sense of and manage illness by accepting it as a part of life and moving on with their lives. Moreover, in this study, most patients felt optimistic about the future and found reassurance in aspects like the excellent care received within the NHS, the trust and professionalism of their care team, thyroid cancer statistics, sound monitoring and self-resilience good support system. As the study participants, unlike the participants of Harper’s study, have live predictions comparable to those without cancer, their priority is to move on and return to normal life.

### **Positive changes in life**

In some rare cases, the thyroid cancer experience brings positive psychological changes. Two participants reported this. The changes happened through internal work that they did as well as support from services including CBT and life coach. Interestingly, both participants suffered from postoperative complications, psychological symptoms and fatigue. This phenomenon is referred to as post-traumatic growth and is well documented in the psychological literature (Peterson *et al.*, 2008). Some people experience substantial growth after a stressful and life-changing event (Peterson *et al.*, 2008) due to enhanced personal strength after cancer diagnosis (Misra *et al.*, 2013).

Moreover, participants of the study reported positive changes in their lifestyles and choices. Some participants experienced feeling more appreciative, being more mindful about health, leading a healthier life, volunteering to help others, and gaining more life experiences. All these actions may improve people's daily lives. However, others experience the feeling of being lucky that their cancer experience was not too bad and could have been worse if they had chemotherapy. Previous literature has reported that cancer survivors experience positive changes in their life. Other research supports the findings of this study. For example, Anh *et al.* (2016) and Gallop *et al.* (2015) reported that some of their participants also reported feeling lucky or experiencing positive lifestyle changes, changes in life outlook, and changing jobs to spend more time with family. It could also be attributed to the phenomenon called post-traumatic growth, briefly discussed above.

### **Isolation from other cancer patients**

Many participants of the current study experienced a sense of isolation from peers and other cancer survivors. Isolation can be literal for patients who undergo radioactive iodine treatment and are isolated for many days from their families and all close physical contact with other people, but also psychologically as patients feel they cannot relate to other patients because of how rare and specific thyroid cancer and its treatment are. The results of the present study suggest that it can be particularly stressful for mothers of young children as they also have to separate from them when they leave the hospital. However, one person said they did not mind having a little break from their family. Another study also explored the phenomenon of isolation in thyroid cancer. However, they looked at young adults only. Still, the results are relatable. (Easley, Miedema and Robinson, 2013) looked at the concept of isolation in young thyroid cancer patients. They looked at isolation from other patients with cancer and support programs, the isolation during RAI treatment, and isolation from peers without cancer. Concerning

isolation from patients with other cancers, participants felt difficulty relating to them. Isolation from peers was expressed as a lack of common understanding as other young people had never experienced a severe disease. Some of the peers expressed a carefree attitude to their friend's disease, which was distressing. One participant in this study explained that the concept of cancer in such a young person is foreign among her friends. Thus, many friends did not know how to behave and ended the relationship. As seen in the results of this study and supported by literature, some participants may also be dealing with isolation from other cancer patients and abandonment from some of their friends. It is especially the case in younger participants and may also be linked with the fact that younger participants tended to have more difficult lived experiences than older ones.

#### **5.2.4 Support**

##### **NHS support provision**

There were differences among this study's participants regarding their satisfaction with having the opportunity to access support. Most participants accessed some form of charity support, mainly BTCT and McMillan. Almost half of the participants stated they did not need support even if they had contact with a charity or support offered by the hospital or GP. The research confirms that patients decide not to access available support mainly because they feel they do not need support (Easley, Miedema and Robinson, 2013). It seems that most of the participants in the present study have no needs or are happy with the support they were offered or accessed. It is in some way contradictory to current evidence in the literature as most studies suggest substantial gaps in support provision (Roberts, Lepore and Urken, 2008; Banach *et al.*, 2013; Easley, Miedema and Robinson, 2013; Hyun *et al.*, 2016).

##### **Support from Butterfly Thyroid Cancer Trust and other cancer charities**

Most participants of the present study that accessed BTCT information, support or both were very grateful for it. People found their website, information pack, Facebook group, Twitter, and DVD informative. Moreover, some participants of this study had treatment in RAI suites which were newly decorated by the BTCT initiative, and they were delighted with the effect. It improved the experience of the RAI treatment. On page 23 'The Butterfly model' system of cooperation and clinical support between the cancer treatment centre and BTCT is described. They have received many positive comments from patients (Farnell, Bliss and Mallick, 2018). None of the patients that took part in the present study had the opportunity for this kind of support, but they were all very familiar with the BTCT charity and their information, and some

of them had support over the phone or by email. Moreover, most participants in this study were recruited from an advert posted on the BTCT Facebook page.

Many people found support in other charities, including Macmillan Cancer Support, Maggie's, Trekstock (Young Adult Cancer Support) and local cancer support centres. Overall, 15 out of 25 people accessed charity support which is more than half of the participants. A small number of participants (2) found volunteering or fundraising for the charity beneficial for their wellbeing. One of the participants finds it therapeutic to provide peer support to other cancer patients. They found it challenging but very rewarding. Volunteering improves wellbeing as it provides the opportunity for meaningful social interaction and improves happiness (Thoits and Hewitt, 2001; Gagné, Ryan and Bargmann, 2003; Weinstein and Ryan, 2010).

In 2004, NICE published guidelines on 'Improving Supportive and Palliative Care for Adults with Cancer' (Excellence, 2004), where pivotal importance is given to supporting services for all cancer patients; however, despite this, there is very little published information about evaluating these services from the perspective of a cancer patient (Young and Snowden, 2019).

### **Barriers to accessing support**

With Thyroid cancer patients, there are no actual targeted interventions specifically for them. Some participants in the present study expressed that they did not feel like the support offered by the NHS or cancer charities was adequate for their needs (bearing in mind that not everyone was aware of the existence of BTCT though they should have been made aware on diagnosis). However, most participants were recruited with support from BTCT; thus, this study sample may be more familiar with the charity than other patients. In addition, some people felt their cancer was not severe enough to justify needing support from, for example, Maggie's Centre. It has been reported in the literature that people did not access the support needed due to feeling unworthy of support programmes and others due to lack of need for it (Easley, Miedema and Robinson, 2013). Some participants of the present study who accessed the support said that because thyroid cancer is so rare, they could not find anyone who would understand them. Moreover, some participants also said they would not feel comfortable being among very sick people while they look so well and seem healthy. Some stated that they would not relate to those people because of their older age. It was mainly younger participants with those concerns. The current study provides additional information about possible barriers to accessing support by thyroid cancer patients.

## **Facebook Group support**

Many people who participated in the present study became members of Facebook thyroid cancer groups and found them helpful. Facebook groups can provide an invaluable source of support and information. There is a record of groups on FB of people with chronic conditions even back in 2009 (Gaddy and Topf, 2021). Looking at current studies regarding patients' use of social media, the authors concluded that, especially in rare conditions, support received from fellow patients could be very beneficial (Gaddy and Topf, 2021). Many participants in the current study have experienced this. For example, participants communicated with other thyroid cancer patients for advice about a low-iodine diet, for support, for comparison of their journey, comparison of treatment management between different countries and treatment centres within the UK. However, not all participants found FB groups helpful. One participant could not relate to other patients on FB groups due to their age. Some people stopped being members of FB groups as they just wanted to move on and did not want a constant reminder of their cancer on their Facebook feed.

## **Support and relationship with health care professionals**

Relationship with health care providers is one of the vital aspects of the cancer journey that can positively affect people's whole experience of thyroid cancer treatment. Communication with HCPs is one of the most critical factors affecting their experience in people with thyroid cancer taking part in this study. Other studies report similar findings (Gallop *et al.*, 2015; Singer *et al.*, 2016). Most participants were satisfied and happy with their relationship with their leading doctor. This is also the case with participants of other studies. They were perceived as providing "enormous" help (Anh *et al.*, 2016).

Moreover, personal touches are valued (Anh *et al.*, 2016). In the present study, a few participants mentioned that the personal approach of their doctor was essential for them. For example, one participant was very pleased that when they got their results, it was their consultant who rang them personally. In another example, one of the consultants asked participants to call him by his nickname. Thus, small gestures like that can impact participants and their cancer experience in a positive way.

Health care professionals are an essential source of support. However, a lack of support from HCPs is sometimes reported in studies. For example, 33.8% of participants felt unsupported by their care team (Aschebrook-Kilfoy *et al.*, 2015; Applewhite, White, *et al.*, 2016). In the present study, a few people reported that they were not happy with the support they received or did not

receive from their healthcare team, especially regarding emotional support. For example, a few respondents said that the emotional side of the process was never mentioned or acknowledged.

Clinical Nurse Specialists are pivotal in managing diseases (Fulton, Lyon and Goudreau, 2020; Ulit *et al.*, 2020; Leary, 2021). Many participants found the support of a Thyroid Cancer Nurse Specialist invaluable. They provide support and information and are most patients' first point of contact. They answer questions, get back answers, and help patients navigate their multi-services journey. Unfortunately, not all patients have a TCNS available to them. In that case, their main person of contact includes their consultant's secretary or ENT nurses. Due to the lack of a critical person, a few participants mentioned that they were not sure whom to contact if they had questions about their specific case, which was distressing. Nurses are essential in supporting the quality of life of people with thyroid cancer. They can educate, strengthen their social support and educate patients about self-management of symptoms (Huang *et al.*, 2004). They can also support patients in making informed decisions due to their specialist knowledge about the disease (Kendell and Armstrong, 2018). It has been proved that psychosocial nurse-led interventions can improve mood in recently diagnosed oncological patients (Galway *et al.*, 2012).

#### **5.2.4.1 Support family and friends**

##### **Family**

Most participants felt very supported by their families. Family can be a vital source of psychological support for patients, even though they may not be well informed regarding the disease (Sawka *et al.*, 2009). Most participants in the present study were married or lived in a partnership. Three participants were single or divorced. One of the primary sources of support for present study participants was their life partners. Participants valued their partners for their presence, moral support, keeping them positive, taking them places, their company at appointments, and financial and childcare support; having a partner improves their quality of life and decreases levels of anxiety and depression (Taïeb *et al.*, 2009). Some sources in the literature claim that marital status is not correlated to decreased quality of life in thyroid cancer patients (Hoftijzer *et al.*, 2008). Although the literature results are not unilateral, it was clear that having a partner was highly appreciated and valued as a source of support during thyroid cancer. Moreover, most childcare responsibilities during treatment and hospital stays fell on a partner or close relatives like participants' mothers. The situation was easier for participants with older children.

The family did not support some participants in the present study. However, they represented a minority. In the literature, relationships with friends and family and their support have a detrimental impact on people's wellbeing and quality of life (Huang *et al.*, 2004; Sawka *et al.*, 2009; Gallop *et al.*, 2015; Singer *et al.*, 2016). Other studies also report that some participants do not have good family support (Rozema, Völlink and Lechner, 2009; Aschebrook-Kilfoy *et al.*, 2015; Gallop *et al.*, 2015; Applewhite, James, *et al.*, 2016). A few participants of the present study reported feeling a lack of understanding from family. Some family members did not think it was serious, while others were so distressed that they were more upset with their suffering than the participant with thyroid cancer. Lack of understanding was also reported previously (Gallop *et al.*, 2015). Family and friends are an essential source of support and comfort for patients with thyroid. However, not all patients have that strong family support. It is especially the case for people without a partner. Damage to the relationship due to the hardship of thyroid cancer has been reported in both the present study and the literature. One participant from the present study was broken up with by her partner during treatment as he could not deal with the situation. Moreover, a few others experienced marital difficulties though they had been mainly resolved by the time of the interview. In the literature, one study reported no changes in family relationships, 57.1 % and 11.6% reported a negative impact of thyroid cancer on relationships (Schultz, Stava and Vassilopoulou-Sellin, 2003).

## **Friends**

Another critical source of support is friends. Relationships with friends and their support are significant for patients with thyroid cancer and have a detrimental impact on their experience (Huang *et al.*, 2004; Sawka *et al.*, 2009; Gallop *et al.*, 2015; Singer *et al.*, 2016). Most participants in the present study had great support from their friends. However, several participants were disappointed with a few of their friends. Lack of care and ceasing contact were the primary complaints. It was not very pleasant for some of the participants

### **5.2.5 Effect of thyroid cancer on work and finances**

#### **Work**

Many people in this study had their work affected by thyroid cancer. Some had changes to their role, and a few participants missed out on promotions and career advancements, went on to early retirement or had to prolong their full-time studies. Some people struggled with fatigue and cognitive aspects of their job after treatment. In a recent study, 12.3% of survivors do not return to work five years following a thyroid cancer diagnosis. It is how big of an effect a 'good

cancer' can create. However, about half of the people from the current study had positive experiences with work being very supportive. Some participants in the present study reported that their work is not very supportive of their cancer journey. Most of the time, the manager and their attitude (not being kind) and flexibility (for example, time off work for appointments, sick leave) matter the most, as colleagues are usually supportive. On the contrary, unsupportive leaders affect work-family conflict, job satisfaction and emotional distress (Mathieu *et al.*, 2014). For example, two participants in the present study left their employment due to unsupportive managers. On the other hand, one participant stated that having major neck surgery does not constitute a prolonged absence from work for their manager. Another participant stated that struggles and stress regarding work was the most significant and challenging issue that affected their wellbeing during the whole thyroid cancer journey.

## **Finances**

A few participants in the present study had their financial situation affected by thyroid cancer, which they found distressing. Thyroid cancer treatment may affect people's financial situation, adding to the emotional and physical burden of the disease (Gallop *et al.*, 2015; James *et al.*, 2018). However, other authors argue that although some participants may be affected financially by their disease and its implications, there was no effect of a financial burden on their quality of life (Roberts, Lepore and Urken, 2008). The present study's results point to a different conclusion. Many participants stated that they were distressed with their financial situation.

Moreover, sometimes the change is for a long time or forever. Financial difficulties are more common with thyroid cancer than other malignancies (Ramsey *et al.*, 2013). A recent study reported that 61.6% of participants indicated income decline within five years of a diagnosis of thyroid cancer (Creff *et al.*, 2021). In retrospect, the financial situation is a sensitive topic. People are more likely to talk about their other issues than financial troubles. However, looking at the previous paragraph about workplace issues, it can be deduced that their financial situation has decreased for many people. Missed promotions, early retirement, changing jobs to something less challenging, all these changes bring financial repercussions. Moreover, research suggests that financial decline is widespread, and the impact on wellbeing might be very high. This issue should be further explored in research as it shows inequality in the employment and financial areas of people with thyroid cancer, which should be addressed. It may be explained by more thyroid cancer patients being of working age.

### 5.2.6 Summary

To summarise, the treatment experience was positive for the majority of participants. However, there were some complaints and negative experiences. The results of this study regarding possible complications and RAI treatment being anticlimactic are in line with previous literature. However, the prevalence of complications among participants of the present study was much higher. This study provided original results suggesting little difference between people who had two surgeries when compared to people who had one surgery, as well as regarding positive or negative experiences that mainly related to physical symptoms and experience of care within the NHS. This study also provided information about important information gaps for patients. Moreover, participants expressed concerns that some nursing staff looking after them during surgery and hospital stays for RAI treatment had very little knowledge of their needs and mistakes were made due to this.

One of the biggest impacts on the experience of people with thyroid cancer are factors from the personal domain, including psychological and physical factors. Participants try to make sense of the condition by learning about their illness, carrying on with life and feeling hopeful about the future. Literature also supports that most people experience significant distress in various stages throughout their journey. For present study participants, it was often the first health-related severe life challenge they faced and generated many negative feelings. Current literature does not address how patients with TC and survivors find meaning in their disease. Moreover, this process is interrupted by referring to thyroid cancer as a 'good cancer' which only makes people feel more confused and unjustly treated. Therefore, it is essential to let people find their way to come to terms with it. In this study, participants tried to make sense of the condition by learning about their illness and being pragmatic, carrying on with life and trying to feel hopeful about the future with encouragement from information and HCPs.

Although most present study participants had their support needs met, a few were very disappointed with that area of care provision. Some participants said that they did not receive any information about support opportunities, and their care team never addressed their psychological needs. They felt support was never mentioned during their treatment. This result aligns with current literature but only refers to a minority of this study sample.

Physical side effects, both short-term and long term are well documented in the literature. The present study provided more information about those symptoms' practical and life implications. For example, fatigue affects some patients' daily life, like being able to play with children or

walk their dog, as well as affecting major life areas like employment and decisions about a career which has lifelong effects on finances.

Contrary to previous literature suggesting that most support needs of patients with thyroid cancer are unmet, most present study patients were happy with the support options given or had no support needs to date. However, some participants did not feel supported or given information about how to access support. In addition, barriers to accessing support were identified and included feeling that their cancer is not severe enough to waste professionals' time and unable to relate to patients with other cancers due to age and differences in cancer characteristics.

Relationship with HCPs is yet another critical area of the thyroid cancer experience. In the present study, patients reported that personal touches greatly impacted them. The support of a thyroid cancer nurse is pivotal for providing information and support and being the first point of contact for any questions and concerns. Moreover, in this study, most patients were well supported by their family and friends, especially their life partners. Moreover, getting through thyroid cancer may impact existing relationships with friends and family. Break-ups, marital problems and disappearing friends were reported among patients in the study.

Many people have their employment affected by thyroid cancer. Many participants had to face some life-changing decisions. It is also reported in the literature. Management support proved very important to support participants throughout the treatment with flexibility and understanding. On the contrary, unsupportive management was the reason for many stresses and even having to leave jobs. Finances are closely related to the employment situation. The study results and literature point toward a conclusion that many people with thyroid cancer had their financial situation significantly affected by the disease. The present study provided insight into the choices people had to make and the sacrifices they faced.

### **5.3 Implications and recommendations for practice**

#### **General advice**

- Diagnosis is very distressing for patients. Some patients reported being alone when receiving a diagnosis. HCPs need to ensure participants bring their family or friends for support when receiving their diagnosis. It happens for many patients but not for all. It should be a standard practice so that all patients can have family support when receiving diagnosis.

- Thyroid cancer can occur in children, young adults, and older adults. People of all ages should be encouraged to contact their GP if they see any changes in the neck, voice quality and sudden onset of unexplained fatigue.

### **5.3.1 Hospital care and treatment**

#### **Surgery experience**

- Most participants are happy with their surgery. Factors that affect the surgery experience include surgery being physically bearable and outstanding care. Negative factors include uncaring attitudes of hospital staff, slow response to buzzers, inadequate pain control, negligence, being rushed, forgotten, and staying with random patients. It is essential to understand the positive and negative factors that affect patients' experiences to learn, understand and design interventions to overcome negative factors and maintain and improve the positive experiences of patients. For example, patients should be assisted in being as symptom-free as possible with the use of pain control medication and antiemetics medication. Moreover, caring and compassionate care is critical, and positive interactions can impact the overall experience of treatment. Even one negative interaction can impact people for a long time. Therefore, it is essential always to be reflective, supportive and kind when dealing with all patients, including those with thyroid cancer. Health care staff should always strive to provide excellent care according to the standard, requirements and codes of conduct of their professional body, for example, NMC (Nursing and Midwifery Council), GMC (General Medical Council) and AHPF (Allied Health Professions Federation).
- It is essential to have scar-related post-surgical support to assist with symptoms related to the scar when needed. In addition, patients should be informed about tightness, massage and the healing process.
- Long-term side effects after thyroid cancer surgery in patients are common. There is also recent data about overdiagnosis. Therefore, careful consideration must be given when recommending treatment options to patients to ensure the surgery's benefits outweigh the risks of complications and long-term symptoms. Moreover, patients' well-informed opinions should be taken into consideration.

- The most common postoperative symptoms include pain, stiffness, tiredness, voice problems, swelling, and swallowing issues. Patients should be offered support with any issues, and referrals should be made when appropriate if the symptoms persevere after the recovery period finishes. The key person involved in their care could be the person responsible for that, for example, TCNS or another named nurse.

### **RAI experience**

- A worry regarding RAI is widespread; information provision should be comprehensive, especially on the patients' main worries, such as side effects, risks for family and children, fertility, and risks of other cancers in the future. These were common fears and could be quickly elevated through counselling or information provision.
- Patients who had their RAI treatment in suites renovated by BTCT had a much better experience of isolation. It shows how the outstanding efforts of the charity are very worthwhile in enhancing the patient experience. Other suites could be upgraded to a similar standard to improve the patient experience.
- There is some confusion among patients about the low-iodine diet. Clear information and practical advice are advised.
- While some people did not experience any symptoms related to RAI, symptoms commonly reported were taste alterations, sore saliva glands and tiredness. Support for managing these symptoms should be provided when needed.
- Fatigue can be severe, life-changing, and affect everyday lives in many ways. Patients should receive support, counselling, intervention and advice to help them cope with fatigue.

### **Follow up**

- Follow-up appointments, although appreciated by many, can induce anxiety. Therefore, it should be taken into consideration at follow-up appointments. It is also an opportunity for any screening and referrals. For example, referrals for talking therapies or counselling for patients with signs of anxiety or depression or the referral to speech and language therapist for patients with voice problems. Regular long-term screening,

including physical and psychological complaints, should be a part of optimal care for thyroid cancer patients and survivors.

- Many people suffer from symptoms of thyroid hormone dysregulation following their treatment. Therefore, reaching an optimal clinical dose that eases any symptoms is essential.

### **NHS system complaints**

- Lack of continuity of care or disjointed treatment causes distress. It could be minimised by having a critical health care professional like TCCNS or named key worker. Various parts of the treatment are done by different departments and managed by different care teams. The present study established that the lack of a key person coordinating the cancer journey is bothersome and problematic for many participants. Patients must have a key contact person, usually a TCNS or another nurse, to access reliable information and support when necessary.
- A small number of thyroid cancer patients mistrust NHS services. It is a very distressing situation for them. Support and counselling are needed to reassure patients but at the same time to respect their wishes.
- Complaints about the NHS system include missed appointment letters, surgery on the wrong side of the thyroid, lack of preparation and organisation for follow-up appointments, mistakes during surgery, long waits between treatment, disjointed treatment, overdiagnosis (patient's own opinion) and conflicts with GP about decreasing levothyroxine. Some complaints are out of the control of HCPs, such as long waits between treatments, as these are necessary for clinical outcomes. However, other complaints like missed appointment letters could be overcome by sending a message to patients' phones with confirmation of their appointment. Moreover, patients should be empowered to discuss with their GP their new hormone replacement requirements (the dose of hormones is much higher than the GP usually would prescribe) and, if necessary, give them a relevant 'information card' (used in practice in the North of England) or connect their GP with the thyroid cancer care team.

### 5.3.2 Information provision and support

- It is essential to address gaps reported by patients in information provision. Significant gaps in information include psychological support, psychological and physical side effects, long-term side effects, and levothyroxine advice. Patients often turn to internet support groups to fill in the gaps. Thus, they must have high-quality, thyroid cancer-specific information readily available.
- A Thyroid Cancer Nurse Specialist or another named nurse is vital in providing patient information and support and being the first point of contact. Some centres do not have this service. All patients should have access to TCNS, even in a small capacity. Due to thyroid cancer being a rare disease, many trusts share TCNSs. This can provide a suitable solution when employing a TCNS in smaller centres where not many people are treated for thyroid cancer is not financially viable.
- Decision-making is very important in any illness. Patients with thyroid cancer should be included in decision-making regarding their treatment. All risks and benefits should be presented to them, and their opinion and choices should be respected.
- Many patients find that being busy with other exciting activities helps them cope with thyroid cancer. Therefore, activities, sports and hobbies should be encouraged to support the wellbeing of thyroid cancer patients and survivors.
- A patient may find it difficult to relate to other cancer patients, which could hinder them from accessing any support. Patients should be encouraged to access various forms of support as everyone is different and has different support needs. Moreover, more education could be provided to support thyroid cancer services to improve their ability to support patients. For example, staff on wards where patients have surgery and RAI treatment should be familiarised with this group's care requirements.
- Thyroid cancer can alter patients' relationships. Patients without good social support should be identified and supported.
- Spiritual needs should be met in a hospital setting. Healthcare staff should know the patients' religious beliefs and include this in a care plan. That is why it is advisable to assess patients' religious needs in a healthcare setting.

### **5.3.3 Psychological effects of thyroid cancer**

- People who experience significant distress at the time of diagnosis should receive written information and be offered access to support services.
- Fear of recurrence is prevalent in the thyroid cancer community. Support should be offered to help patients cope with this long-lasting fear. Other sources of fear and anxiety include prognosis, metastasis, other cancers, death, and side effects of treatment.
- All female participants with thyroid cancer that have not yet had children expressed deep worries about difficulty getting pregnant and risks for the baby. Therefore, this group of patients should be provided counselling in this area.
- Anxiety and depression symptoms can start during the thyroid cancer journey. Also, pre-existing anxiety and depression can negatively impact the experience further. All patients should be screened for these disorders throughout their treatment, recovery and beyond. It happens regularly in centres that have services of TCNS. Moreover finally, interventions or strategies should be designed to support patients in overcoming their many fears and anxieties.
- Most people often encounter the term ‘good cancer’ during their journey. It has a mainly negative impact on people. The term ‘good cancer’ should be avoided at all costs in clinical and supportive settings.
- Post-traumatic growth can be observed in some patients. Even people suffering from complications and persistent disease, with the proper support and internal work, can experience positive changes in their life. Providing people with the proper support is vital to help them flourish even after suffering from thyroid cancer.

### **5.3.4 Work and finances**

- Work-related difficulties are common in people with thyroid cancer. Therefore, advice regarding possible work effects and practical advice should be offered.
- Present and future finances can be affected for many years after treatment. Therefore, advice and information should be provided.

Like all other patients, patients with thyroid cancer should be treated in a kind and compassionate manner. It is not only an expectation but a requirement of conduct for all professionals working in the hospital and part of the values that all NHS employees should follow even if they are not obliged by a professional body. Information for patients should be thorough and thyroid-specific. Questions should be encouraged, and a contact number of a person that can answer all questions should be provided. Patients should have access to information regarding support services and be referred when needed. All referrals should be made when patients suffer from long-term physical or psychological symptoms. As seen above, most recommendations are regarding information provision, support, caring attitude of HCPs and hospital staff and managing side effects and symptoms. Thus, these recommendations can be realistically adapted in practice.

It is essential to acknowledge that the NHS may not be able to provide specialist counselling/support in all the areas discussed. For example, work and finances are specialist support areas, and the NHS could most realistically make referrals to agencies that offer this type of specialist support. In other areas, although counselling and support should ideally be provided, NHS staff being more aware of these issues in their patient conversations would still represent some progress.

#### **5.4 Study strengths and limitations**

The study's strength is that it examined in detail the impact of diagnosis, treatment, recovery and follow-up on participants' lives. It established a range of factors affecting the experience in different stages of the journey, which is an original contribution to current knowledge about experiences of having thyroid cancer. Moreover, this is the first study of thyroid cancer with a holistic approach, looking at various aspects of life and appreciating human life's multilevel and complex nature. Until now, the measurement of HRQoL failed to provide answers to why patients struggle with decreased quality of life despite a favourable prognosis. Qualitative data can help to answer that question and provide insight into the mysterious world of other people's lives.

The study faced a major setback at the beginning of recruitment due to a global pandemic, hindering face-to-face contact. Although face-to-face interviews would have been more insightful, the study reached its aim and all three objectives. The original research plan was to include only prospective participants. Unfortunately, it did not happen due to this unforeseen situation. Comparing the quality and amount of information from prospective longitudinal and

retrospective participants, the researcher hasn't noticed a significant disadvantage in data quality between those two groups. However, this is not a longitudinal study like it was planned to be.

Retrospective qualitative research is often criticised for the risks associated with failures of recall (recall bias) (De Vaus and de Vaus, 2013), but the researcher still gathered detailed information about the experiences and feelings of participants. Similarly, it is sometimes thought that telephone interviews do not provide the same opportunities to develop rapport, affecting the data level (Novick, 2008), but the participants shared a lot of personal and sensitive information with the researcher. From the researcher's perspective, it is the researcher's skills in building rapport and interacting with people that yields deep and personal data and not the mere fact of a tool used for collecting the data.

Similar research in the future could be improved. For example, three interviews starting at a point of diagnosis and a strict prospective longitudinal approach would be suited for either quantitative methodology or mixed methods when precise measurement tools can be used to compare the quality of life or wellbeing at different treatment points. It would also allow the research to precisely track changes in factors affecting experience.

Another limitation of this study is the sampling approach. Most participants were recruited via a self-selection process. Therefore, the study may have a disproportionate number of those dissatisfied with their medical care and experience. It was acknowledged and considered at every data analysis stage, particularly when discussing dissatisfaction with medical care. For example, a disproportionately high number of participants in this study had complications after the surgery. In general, only a tiny percentage of people have those complications. Also, two participants had surgery on the wrong side of their thyroid. Its sporadic occurrence is called 'never event', which should never happen in healthcare. Also, a few participants had metastasis, a very high number for a sample of 25 patients. Hence, this is not a representative sample. It should be taken into consideration when considering the results of this study. In future publications, the self-selection bias will be explained so that all readers can judge the suitability of the study's results for their own use and how relatable the results are for their patients.

Finally, participants that took part in the study were mainly recruited with help of the BTCT charity. Since many recommendations are centred on the importance of the type of support that this particular charity offers, it is important to list this as a limitation.

## 5.5 Future research

This study used a phenomenological method with good results. The study explored the lived experience of thyroid cancer and the role of different factors affecting experience for this group of patients. However, there are a few ways to improve the quality of this study or build on it to create a more extensive study in the future. For example, a similar study with different sampling methods that avoid self-selection bias would produce more generalisable results. For example, recruiting consecutive patients from clinics. Moreover, a more culturally diverse sample should be used in future research.

A mixed-methods study with a quantitative element could establish how people's experiences affected the quality of life or wellbeing. Larger, multicenter future studies looking at factors affecting the quality of life could use a mixed-methods approach and include more patients, interviewing them a few times at regular intervals starting from before diagnosis. The quantitative aspect of the study could utilize a standardized thyroid cancer-specific quality of life or wellbeing tool. In this case, mapping changing factors on a timeline would be more precise as it would also indicate changes in the overall outcome of quality of life. This study is an important starting point for more studies into the areas of interest identified. For example, this study concluded that the quality of NHS services and care are pivotal for creating a positive experience in thyroid cancer journey. However, more research on a larger scale is needed into care and complaints against the NHS from the patient's perspective to learn from them and improve services. For example, the impact of delays and cancelled treatments on the lived experience of people with cancer. Although sometimes delays are inevitable, the effect on patients can be detrimental to their whole experience.

Questionnaires usually measure quality of life. The researcher looked at the Short-Form Health Survey SF 36, ThyPRO, EORTC QLQ-C30 and Macmillan Concerns Checklist. Whilst some of these are good (Macmillan Concerns Checklist can identify many concerns from various areas of life), none look at any complaints, worries or issues that patients may have with the healthcare system or providers. The holistic wellbeing or quality of life scale could be designed to capture all nuances or holistic experiences, which would be very helpful in measuring the prevalence of various factors. However, some factors should be included, predominantly factors related to satisfaction with care provided and treatment. It is currently missing from many tools measuring health-related quality of life.

A quantitative tool could be developed based on the factors identified in this study. Then, a quantitative longitudinal evaluation of the factors could be created to explore how factors change over time, throughout the treatment, recovery and beyond. Also, comparisons between different demographics and treatment groups could be made. For example, factors affecting people with different treatments, age, gender, marital status, and employment could be measured and compared. A strict quota sample could ensure the equal distribution of demographic/social factors to allow for comparison.

Another interesting topic from this study is the barriers preventing thyroid cancer patients from accessing support. More research should be carried out on this topic. This study identified difficulties relating to other cancer patients, feeling unworthy of support, and their illness is not severe enough to bother support services. This topic should be explored, and intervention developed to support patients and encourage them to access services that may benefit them in the long run.

The topic of overdiagnosis and the necessity of different parts of treatment is also of note. As the treatments carry many risks, decisions about treatment should be carefully made and include the patients themselves. More research should be directed into the benefits and negatives of surgical intervention versus active surveillance. It would give patients viable options that have the potential to enhance their experience.

## **Chapter 6 Conclusions**

### **6.1. Addressing the aim and objectives**

This study aimed to explore the lived experience of people through diagnosis, treatment recovery and follow-up. The study reached its aim as it did explore the whole journey that patient goes through and how participants lived through this experience. The thesis addressed all three objectives. The first objective was to explore the experience of thyroid cancer from the participants' perspective. The use of in-depth semi-structured interviews allowed for an exploration of participants' experiences, feelings and reflections about their journey. The second objective was to explore the impact of hospital care and treatment specifically. These topics were part of the interview guide to ensure each participant expressed their experiences and thoughts. These topics were discussed extensively by the respondents. The reason is that there is little information previously published about experiences of treatment and hospital care. Hence, this study provided an important insight into the experience. The third objective was to explore negative and positive factors affecting the lived experience of thyroid cancer. The content analysis provided a list of the most common negative and positive factors that assisted in establishing four main areas of unmet needs of patients with thyroid cancer. This also helped shape recommendations to practice. The fourth objective was to provide recommendations for improvements to practice in the care of thyroid cancer patients. The recommendations for practise have been provided. This recommendation can be beneficial for health care professionals, policymakers, and the charity that partially funded this project.

### **6.2 The significance and implications of findings**

#### **Main results**

There is no doubt that the diagnosis and treatment for thyroid cancer affects many aspects of people's lives. Their psychological health, physical health, relationships, employment and finances can be impaired. Exploring hospital care and treatment yielded many exciting insights into hospital care experiences and treatment. This study's participants had good and bad experiences with care and treatment. Positive factors that make the surgery experience positive are compassionate and professional care from HCP and manageable physical side effects after surgery and during recovery. The opposite can impact the experience negatively. The main complaints about the RAI stage of the treatment were isolation and loneliness. Information provision is vital for participants. There are gaps in the provision that participants of the study identified. The information provision gaps include possible long-term treatment symptoms,

practical information about levothyroxine and information about psychological support. Thyroid cancer diagnosis treatment and follow-ups generate a lot of anxiety and fear that can last many years after the treatment is completed. The anxiety and fear in regards to outcomes, treatment, recurrence and potential side effects were very common.

### **Unmet needs of patients**

Many of the recommendations are regarding patients' unmet needs for information and support needs. Thus, the main recommendations of this PhD thesis are to ensure that the cancer care centres that provide care for thyroid cancer patients have a Thyroid Cancer Nurse Specialist or a named key worker as they are in the best position to fulfil most information and support needs, even if this means making a referral to specialist services to help with psychological and physical symptoms. Those services may include psychological therapies, charities support, physiotherapy, speech and language therapy or any other health or social care services that may address patients' needs. This study suggests that a thyroid cancer specialist nurse can be particularly effective in this role. However, the contact may also be remote in less busy centres, or an oncology nurse specialist can take on that role that deals with multiple types of cancers.

### **Implication to practice**

It is imperative to have a tailored, person-centred approach to healthcare and support services. The key is to be flexible and understand how different people are and how differently they can perceive events. Knowledge of the main negative and positive factors that can affect experiences at different times could assist Health care Professionals in identifying patients with high levels of emotional distress to provide them with additional support. A favourable prognosis, excellent treatment experience and physical health do not necessarily mean that patients are doing well. The results of this study may encourage future research and advise clinical practice to be vigilant when screening patients, and provide good quality, thorough information and compassionate care at every interaction.

### **The Contribution to the knowledge**

This study provides a significant and original contribution to knowledge. It provides a holistic view of the experience of thyroid cancer. It explores the whole journey of participants, from finding the lump-through diagnosis and treatment- to follow-up appointments. It also provides information about factors affecting participants and their experience in different process stages. The study identified key unmet needs of patients that can be addressed. Other studies looked at

either measuring quality of life or focused on only one or two aspects of the journey, such as scar or RAI. The present study explored all aspects of the experience from the participants' perspective and only the factors that participants mentioned. The comprehensive recommendations can significantly improve the care and information provision for patients from the perspective of both NHS and the BTCT charity.

### **The reasons for decreased quality of life in thyroid cancer**

The reasons for decreased quality of life in thyroid cancer were unknown though speculated in previous research. The researcher has reflected throughout the study process and had this question in mind when conducting the present study. There are a few observations that are important to note. First of all, thyroid cancer occurs in people younger than other cancer patients and may not be equipped to handle the emotional burden compared to older patients with more life experience. Also, younger participants also had work and childcare responsibilities. Furthermore, patients are informed that they will most likely require lifelong follow-ups because this form of cancer may return many years after successful treatment is completed. Moreover, because this is a sporadic cancer, it is not very well recognised by the general public and healthcare professionals. Thus, the support systems are not developed like in the case of other cancers, for example, breast cancer.

Other factors that could be significant are the fact that so many different teams that provide care and care may feel disjointed, especially if a key worker or TCCNS is not available to coordinate care and support patients. Furthermore, many people suffer from severe tiredness and other symptoms that affect wellbeing. The 'good cancer' label also undermines the experience and confuses people. Finally, complaints against medical services have a detrimental effect on people's experience.

The effort to improve the support and information provision can significantly improve the quality of the experience of thyroid cancer patients. This study demonstrates some of the factors that have an impact on the lived experiences of thyroid cancer patients. While many of these are beyond the control of the NHS, it also points to areas where improved practice and staff knowledge could positively contribute to these lived experiences.

## Appendices

### Appendix 1. Literature Review

#### Quantitative articles Quality of Life in Thyroid Cancer, 45 articles

Measure	Authors	Title	Appraisal	Methodology	Results
Health - Related Quality of Life (HRQoL)	(Gkatzia <i>et al.</i> , 2021)	Quality of Life Survey Following Radioactive Ablation in Patients with Differentiated Thyroid cancer.	Longitudinal design up to 1-year post-diagnosis. Small sample. Single centre, single survey.	Cross-sectional, 85 patients, Short-Form Health Survey (SF-36).	TC treatment affects HRQoL across domains even with favourable prognosis. Hypothyroidism symptoms improve.
Mental health measures	(Dionisi-Vici <i>et al.</i> , 2021)	Distress, anxiety, depression and unmet needs in thyroid cancer survivors: a longitudinal study	Longitudinal design but up to 1 year only. No control group, small sample size, high drop-out. Didn't investigate details of previous psychological comorbidities. Multiple measuring tools.	73 participants disease free, Distress Thermometer, Hospital Anxiety Depression Scale, Supportive Care Need Survey (short form) and Interview for Recent Life Events	Distress, anxiety and depression is experienced by patients even many years after diagnosis.
HRQoL	(Schoormans <i>et al.</i> , 2020)	Negative illness perceptions are related to poorer health-related quality of life among thyroid cancer survivors: Results from the PROFILES registry	Multiple surveys used, national population-based study. Medical notes accessed.	284 patients. Brief Illness Perception Questionnaire; B-IPQ) and EORTC QLQ-C30). Patient-Reported Outcomes Following Initial treatment and Long-term Evaluation of Survivorship (PROFILES)	Negative perception of the disease affects the quality of life. Factors identified: emotional and social functioning, fatigue, nausea and vomiting, pain, dyspnoea, insomnia, appetite loss, and constipation.

Psychological distress, disease perception.	(Husson <i>et al.</i> , 2020)	Psychological Distress and Illness Perceptions in Thyroid Cancer Survivors: Does Age Matter? Olga	Large sample, comparison with other age groups.	293 participants, 84 of them young adults. Hospital Anxiety and Depression Scale (HADS) and Brief Illness Perception Questionnaire. Recruitment from PROFILES registry.	Perception of the disease affects distress. Higher distress regarding perception in adults and older adults.
Quality of Life.	(Giustiet <i>et al.</i> , 2020)	Evaluation of Quality of Life in Patients with Differentiated Thyroid Cancer by Means of the Thyroid-Specific Patient-Reported Outcome Questionnaire: A 5-Year Longitudinal Study.	5-year longitudinal study. No baseline data. No socio-economic data. Included few TC types but groups ranging from 6 to 102. Control group had surgery for benign nodule.	123 adults, ThyPRO and Billewicz scale (BS) to assess disease-specific morbidity	Thyroid cancer survivors scored more for hyperthyroidism symptoms than control groups. TC survivors and control had very similar results in quality of life. There was significant improvement in QoL in thyroid cancer patients. Women have more impaired quality of life and disease perception.
HRQoL	(Büttner <i>et al.</i> , 2020)	Quality of Life in Patients with Hypoparathyroidism After Treatment for Thyroid Cancer Matthias	First study on this topic. International study, small sample.	93 patients, 17 with HPT symptoms (tingling toes and fingers) QoL was measured using the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core (EORTC QLQ-C30) and questions specific to HPT symptoms	Patients with Hypoparathyroidism have significantly more impaired QoL than other thyroid cancer patients.
HRQoL	(Bongers <i>et al.</i> , 2020)	Differences in long-term quality of life between hemithyroidectomy and total thyroidectomy in patients treated	Consecutive cohort. Single centre. Detailed recruitment information. Use of	270 patients, Quality of Life questionnaires: European Organisation for Research and Treatment of Cancer Quality of	No significant difference in HRQoL between total and hemithyroidectomy, apart

		for low-risk differentiated thyroid carcinoma	multiple questionnaires and data sources including thyroid cancer-specific. Low response rate 51%	Life core Questionnaire version 3.0, the supplementary Thyroid Cancer-specific questionnaire module version 2.0, and the Assessment of Survivor Concerns (ASC) questionnaires were	from increased fear of recurrence in patients with hemithyroidectomy
Depressive Disorder	(Choi <i>et al.</i> , 2019)	Depressive Disorder in Thyroid Cancer Patients after Thyroidectomy: A Longitudinal Follow-up Study Using a National Cohort.	Observational study (all data collected from database). Large number of participants. Long follow up (up to 10 years), Depressive symptoms evaluated from visits to psychiatrists and not included self-reported symptoms. No measurement of sources and severity of depression.	3609 participants recruited from Korean Health Insurance Review and Assessment Service- National Sample Cohort (HIRA-NSC). All data collected from the database.	The prevalence of depression is higher in thyroid cancer patients, especially those who were younger and/or from lower socioeconomic background.
Quality of Life	(Haraj <i>et al.</i> , 2019)	Evaluation of the quality of life in patients followed for differentiated cancer of the thyroid	Cross-sectional study with control group. Single contact, single centre study, no baseline or follow up data	124 participants, SF36, Hamilton anxiety and Hamilton depression (HAM-A and HAM-D)	Psychological wellbeing of thyroid cancer patients should be monitored. Factors impacting the QoL the most include RAI and its dose, presence of metastases
QoL	(Hossain, Islam and Khatun, 2019)	Health-Related Quality of Life of Thyroid Cancer Patients	Multiple sources of data (medical notes, questionnaires, face to face interviews). 2 centres. Single contact, no follow up or	246 cross-sectional study, medical record and semi-structured interviews. FACT-G (version 4)	Overall good wellbeing of participants. Income, education, stress, marital status, disease stage were predictors of QoL

			baseline information		
Quality of life	(Li <i>et al.</i> , 2019)	Risk Factors of Deterioration in Quality of Life Scores in Thyroid Cancer Patients After Thyroidectomy	Prospective study. Single centre. Single contact point 3 months after thyroidectomy. T4 not measured (but previous studies show no correlation unless hypothyroidism present)	286 patients, prospective, single centred study. Questionnaire used: Research and Treatment of Cancer Quality of Life Questionnaire Core 30. 3 months after thyroidectomy	Factors correlating with lower quality of life: surgery type, histology result, clinical stage marital status, non-neurological deficit
Health-Related Quality of Life	(Laura <i>et al.</i> , 2019)	Quality of life in patients thyroidectomized for differentiated thyroid cancer	Prospective study, 4 groups by T4 function. Use of three questionnaires. Single contact no follow ups	200 patients, self-reported questionnaires' (Multidimensional Fatigue Inventory MFI, the thyroid-specific QoL patient-reported outcome measure ThyPRO	IT is thyroid cancer experience and not thyroid function disruption that affects QoL. However hypothyroid group showed lowest QoL
HRQoL.	(Nickel <i>et al.</i> , 2019)	Health-Related Quality of Life After Diagnosis and Treatment of Differentiated Thyroid Cancer and Association with Type of Surgical Treatment.	Large sample, high response rate, recruitment from single centre and national cancer registry. Open-ended questions that were content analysed. Many small responses (less than 50 words). Not recording conversation with nurse. No data on previous psychological status. Lower participation among younger TC survivors hence bias.	1005 participants, Open-ended question to explore concerns and outcomes regarded TC diagnosis and treatment	Many issues reported affecting QoL including physical and cognitive ailments. Major issues: fatigue, medication issue, voice, emotional distress.

Worry /Anxiety	(M. Papaleontiou <i>et al.</i> , 2019)	Worry in Thyroid Cancer Survivors with a Favourable Prognosis	large sample, little lacking data, high response rate, recall bias. Single contact study	2215 disease free survivors, 2-4years since diagnosis from registry in state of Georgia and Los Angeles County	Major issues despite good prognosis. Main things people worry about: recurrence (63.2%), putting family at risk (58%), impaired quality of life (54.7%), harm from treatment 43.5%, death 41%
HRQoL	(Ramim <i>et al.</i> , 2020)	Health-related quality of life of thyroid cancer patients undergoing radioiodine therapy: a cohort real-world study in a reference public cancer hospital in Brazil. Consecutive sampling	National prospective cohort, three points of contact (baseline, 1 week and 3 months after RAI)	149 participants, EORTC QLQ-C30 v3 and EORTC QLQ-H&N35	RAI affects HRQoL but it improves with time
Information support, illness perception, distress	(Wiener <i>et al.</i> , 2019)	Information support, illness perceptions, and distress in survivors of differentiated thyroid cancer	Limited clinical data available. Observational study, all data obtained from PROFILES	284Participants. Patient Reported Outcomes Following Initial Treatment and Long-term Evaluation of Survivorship registry. Model (PROFILES)	Negative disease perception needs to be addressed. The way we can address is by information provision to decrease distress
QoL	(McIntyre <i>et al.</i> , 2018b)	Quality of life in differentiated thyroid cancer Charlotte	patients were selected from a patient-doctor forum this could impose bias	82, longer than 6 months from diagnosis. EQ-5D-3L version of EQ-5D	significantly lower QoL compared to average populations and among patients with breast, colorectal and prostate cancer
HRQoL	(Hedman, Djärv, <i>et al.</i> , 2017)	Effect of Thyroid-Related Symptoms on Long-Term Quality of Life in Patients with	good perspectives on long-term effects of TC	279 patients diagnosed with DTC between 1995 and 1998, HRQoL SF-36 and a study-specific	Recurrence as well as fear of recurrence negatively impacts HRQoL. Few

		Differentiated Thyroid Carcinoma: A Population-Based Study in Sweden		questionnaire, 14-17 years after their diagnosis.	patients reported poor QoL. Half of patients still worry after >14 years.
QoL	(Rogers <i>et al.</i> , 2017)	Health-related quality of life, fear of recurrence, and emotional distress in patients treated for thyroid cancer.	single institution, single point of data collection, age bias reported.	169 participants (EORTC) QLQ-C30, the THYCA-QoL, the Emotion Thermometers, and the new FoR screening item	Study revealed many physical ailments in participants.
QoL	(Goldfarb and Casillas, 2016b)	Thyroid Cancer–Specific Quality of Life and Health-Related Quality of Life in Young Adult Thyroid Cancer Survivors	Single contact study. Online recruitment, multiple questionnaires used,	277 of young adults, HYCA-QoL, MCS and PCS of SF-12v1, and derived SF-6D, regression analysis	QoL significantly impacted by many demographic and clinical factors. Lower in female, neuromuscular, concentration and anxiety important factors
QoL	(Lubitz <i>et al.</i> , 2017)	Measurement and Variation in Estimation of Quality of Life Effects of Patients Undergoing Treatment for papillary Thyroid Carcinoma	had pre-assumptions that QoL decreases post-operatively for all participants and that health returns to normal following treatment	117 patients, 3 points in time (Short-Form-12v2® (SF6D), EuroQol-5D (EQ5D), and Health Utilities Index Mark 2 and 3 (HUI2, HUI3))	good general health, QL impacted by psychological and social impacts
QoL	(Metallo <i>et al.</i> , 2016)	Long-Term Quality of Life and Pregnancy Outcomes of Differentiated Thyroid Cancer Survivors Treated by Total Thyroidectomy and I131 during Adolescence and Young Adulthood	limited number and scope of surveys	45 patients, cross-sectional, SF-36 and ISP-25 surveys, and of pregnancy outcomes	QoL in young females not affected. Pregnancy outcomes similar to those of GP
QoL	(Singer <i>et al.</i> , 2016)	Quality-of-life priorities in patients with thyroid cancer: A multinational European	EORTC QIQ-C30 supplemented by list of relevant issues coming from	110 from seven countries patients of EORTC QLQ-C30	Important factors include fatigue, psychological issues including fear

		organisation for research and treatment of cancer phase I study.	systematic review and reduced to 25 items by specialists and thyroid cancer patients.		of recurrence and treatment.
fear/anxiety	(van de Wal <i>et al.</i> , 2016)	Does fear of cancer recurrence differ between cancer types? A study from the population-based PROFILES registry	observational study, data was extracted from PROFILES registry, some limitations regarding measures,	469 participants with melanoma, 861 with colorectal cancer, 688 with endometrial cancer, 218 with thyroid cancer, 103 with non-Hodgkin lymphoma  (EORTC QLQ INFO25, satisfaction scale) and health-related quality of life (EORTC QLQ C30, Short-Form 36-item)	fear of recurrence is universal across cancers. Risk factors include gender, sex and medical factors
QoL	(Aschebrook-Kilfoy <i>et al.</i> , 2015)	Risk Factors for Decreased Quality of Life in Thyroid Cancer Survivors: Initial Findings from the North American Thyroid Cancer Survivorship Study	baseline measures, self-reported data only, only 50 % of cases validated by medical records, social media to recruit participants. Large sample size,	1174 patients mixed-methods: City of Hope-QoL tool ( <a href="http://prc.coh.org/pdf/Thyroid%20QOL.pdf">http://prc.coh.org/pdf/Thyroid%20QOL.pdf</a> ) and qualitative elements of open-ended questions and narrative data.	Determines of lower quality of life being female, young, lower education
Psychosocial Distress	(Buchmann <i>et al.</i> , 2015)	Psychosocial Distress in Patients with Thyroid Cancer.	sample bias explained by authors.	118 newly diagnosed TC patients. Individual retrospective cohort study. Distress Thermometer (DT) and medical notes revision.	High levels of distressed reported.
QoL	(E. M. Gamper <i>et al.</i> , 2015)	Persistent quality of life impairments in differentiated thyroid cancer patients: results from a monitoring programme	aged matched and sex-matched control groups,	439 participants, 284 patients had data measured before and after RAI available. EORTC Quality of Life Questionnaire Core-30 (QLQ-C30)	Important factors: fatigue, pain, dyspnoea.  Good prognosis doesn't grant good QoL. Disturbances

					in daily life and leisure
QoL	(Vega-Vázquez <i>et al.</i> , 2015)	Quality of life-in patients with differentiated thyroid cancer at the general endocrinology clinics of the University Hospital of Puerto Rico.	Patients were recruited from single centre. Scars can change in time. Limited number of patients. Patients segregated according to four group types, n varied from 9 to 42.	75 patients, single centred, prospective observational study, cross-sectional Spanish version of the UW-QoL questionnaire QoL	Minimal effect on quality of life.
QoL	(Choi <i>et al.</i> , 2014)	Impact of Post thyroidectomy Scar on the Quality of Life of Thyroid Cancer Patients.	Single contact, single centre observational study. 4 scar categories but some have mixed features. Scars can also change overtime.	97 patients up to 2 months from surgery, Dermatology Life Quality Index (DLQI),	All scar types affect QoL of TC patients.
Distress.	(Roerink <i>et al.</i> , 2013)	High level of distress in long-term survivors of thyroid carcinoma: Results of rapid screening using the distress thermometer.	Easy to implement short surveys to use with patients in clinical practice, no evaluation of reasons for distress or information when the distress is higher during cancer journey.	205 patients, The Distress Thermometer (DT) and problem list (PL)	Distress is prevalent and difficult to predict. Can't be predicted by clinical or demographic factors.
QoL	(Giusti <i>et al.</i> , 2011)	Five-year longitudinal evaluation of quality of life in a cohort of patients with differentiated thyroid carcinoma.	5-year study, self-report, clinician administered measures, clinical data used.	128 DTC patients, semi-structured psychiatric evaluation, 219 patients after surgery for benign nodule. Billewicz scale (BS) self-administered ad hoc thyroid questionnaire (TQ).	Improvement over time on most of evaluations, especially anxiety and depression. QoL goes back to the level of QoL in people that had surgery for benign

				Hamilton scales for anxiety (HAM-A), depression (HAM-D), self-rated KSQ.	nodules. Worse QoL in older adults and more advance stages of disease.
Psychological wellbeing	(Gómez <i>et al.</i> , 2010)	Psychological wellbeing and quality of life in patients treated for thyroid cancer after surgery	little information about sampling and type of cancer	75 patients, descriptive correlational methodology. Index of Psychological Wellbeing created by Dupuy 1984, SF-36	strong correlation between time from diagnosis and improvement of psychological wellbeing.
QoL	(Lee <i>et al.</i> , 2010)	Quality of life and effectiveness comparisons of thyroxine withdrawal, triiodothyronine withdrawal, and recombinant thyroid-stimulating hormone administration for low-dose radioiodine remnant ablation of differentiated thyroid carcinoma.	Some more significant findings relate to treatments not used currently in the UK as a standard treatment.	291 patients, Comparison study as per title.	indicates that use of rhTSH preserves QoL in patients undergoing RI ablation and affords an ablation success rate comparable to that seen after thyroid hormone withdrawal.
QoL	(Almeida, Vartanian and Kowalski, 2009)	Clinical Predictors of Quality of Life in Patients with Initial Differentiated Thyroid Cancers.	detailed description of participants and inclusion/exclusion criteria. Single centred study.	154 patients, University of Washington Quality of Life questionnaire, cross-sectional study	sex didn't affect the QoL domains, age on affected recreation domain, RAI associated with impact on QoL especially higher doses.
Illness perception	(Hirsch <i>et al.</i> , 2009)	Illness perception in patients with differentiated epithelial cell thyroid cancer	110 consecutive patients	110, Illness Perception Questionnaire-Revised (IPQ-R)	Perception of illness is very subjective and can be emotional
HRQoL	(Pelttari <i>et al.</i> , 2009)	Health-related quality of life in long-term follow up of patients with cured TNM Stage I or II differentiated thyroid carcinoma	Single contact study, age and gender standardised study	341 patients, cross-sectional study, QoL was measured with 15-dimensional, standardised, self-administered questionnaire	Long-term wellbeing comparable to general population. Some decline in HQoL seen in both TC

					survivors and control group.
QoL	(Taïeb <i>et al.</i> , 2009)	Quality of life changes and clinical outcomes in thyroid cancer patients undergoing radioiodine remnant ablation (RRA) with recombinant human TSH (rhTSH): A randomised controlled study.	9-month follow up, prospective clinical randomised trial of good quality.	74 patients, chronic illness therapy-fatigue (FACIT-F) (CES-D, BDI and Spielberger state-trait questionnaire.	rhTSH preserves QoL of patients undergoing ablation.
QoL	(Hoftijzer <i>et al.</i> , 2008)	Quality of Life in Cured Patients with Differentiated Thyroid Carcinoma.	used validated questionnaires and controls matched by age, gender, and socioeconomic status.	153 survivors, Short-Form-36, Multidimensional Fatigue Index-20, Hospital Anxiety and Depression Scale, and Somatoform Disorder Questionnaire)	QoL affected but improving in time. No correlations with TSH levels and QoL. 12-20 years QoL returns to normal. No effects of marital status, country of birth, initial tumour node metastasis stage, total activity of I-131, tumour recurrence, L-thyroxine dose, hypoparathyroidism, and serum FT4.
QoL	(Roberts, Lepore and Urken, 2008)	Quality of Life After Thyroid Cancer: An Assessment of Patient Needs and Preferences for Information and Support.	Varied methods of data collection resulting in interesting input regarding unmet information needs. Small sample.	62 patients, EORTC QLQ-C30, Thyroid-Specific QoL, questionnaire about unmet needs	good quality of life, information needs mostly addressed. Identified some unmet information needs.
HRQoL	(Tagay <i>et al.</i> , 2006)	Health-related quality of life, depression and	Method of withdrawal of levothyroxine is not used	136 patients hospitalised for RAI, cross-sectional study,	HRQoL is massively impacted due to short-term

		anxiety in thyroid cancer patients	anymore in the UK or is used very sparingly only in certain situations.	Anxiety and Depression Scale (HADS), Profile of Mood States (POMS), Beck Depression Inventory (BDI)	hypothyroidism. Measurements of anxiety, depressions and mood disturbance would be used to select patients for extra psychological help.
QoL	(Huang <i>et al.</i> , 2004)	Postoperative quality of life among patients with thyroid cancer.	4 questionnaires. Looked at the contribution of patient characteristics (age, gender, etc), disease-specific characteristics (stage, duration of cure etc).	146 patients, telephone interviews. Quality of Life Index	lower wellbeing 19-36 months after surgery than at 18-month point. Factors correlated with lower QoL fatigue and chills, and for some participants' scar.
QoL	(Botella - Carretero <i>et al.</i> , 2003)	Quality of life and psychometric functionality in patients with differentiated thyroid carcinoma.	variety of QoL and cognitive tests used. age matched control, single sex study (women only), old treatment was present with withdrawal of medication before RAI.	18 women with DTC, SF-36 Health Survey, Nottingham Health Profile (NHP), profile of Mood States (POMS), Visual Analogical Mental Scales (VAMS)	long-term treatment with thyroid hormone affects quality of life.
QoL	(Crevenna <i>et al.</i> , 2003)	Quality of life in patients with non-metastatic differentiated thyroid cancer under thyroxine supplementation therapy.	sex-matched and age matched control group, consecutive patients recruited (representative sample), 5 year follow up.	150 patients, SF-36 Health Survey, cross-sectional study	During first year following diagnosis reduced QoL was reported in "Vitality", "Role-physical", "Mental Health", "Role-emotional" and "Social functioning. However, "Vitality" and

					"Role-emotional" impaired in thyroid cancer patient at 5-year mark.
QoL	(Schultz, Stava and Vassilopoulos-Sellin, 2003)	Health profiles and quality of life of 518 survivors of thyroid cancer.	No information about histological findings, no information if RAI was performed.	518 participants, survey	Good quality of life but have issues for example with thyroid hormone regulation.
<b>Qualitative studies included in the Literature Review (6 qualitative articles)</b>					
<b>Measure</b>	<b>Authors</b>	<b>Title</b>	<b>Appraisal</b>	<b>Methodology</b>	<b>Results</b>
Anxiety and Fear.	(Hedman, Strang, <i>et al.</i> , 2017)	Anxiety and Fear of Recurrence Despite a Good Prognosis: An Interview Study with Differentiated Thyroid Cancer Patients.	information about how trustworthiness was achieved. Maximum variation sampling hence transferability in question. However, authors argue that transferability is possible due to commonality of the anxiety in sample.	21 patients, semi-structured interviews	anxiety is very common in people with thyroid cancer.
'Good Cancer'	(Randle <i>et al.</i> , 2017)	Papillary Thyroid Cancer: The Good and Bad of the "good Cancer"	frequent follow up, Grounded theory	31 participants, 5 points of contact from diagnosis to 1 year after diagnosis. Semi-structured interviews	good cancer invalidates experiences and distress of thyroid cancer
HRQoL.	(Gallop <i>et al.</i> , 2015)	A qualitative evaluation of the validity of published health utilities and generic health utility measures for capturing health-related quality of life (HRQL) impact	Large sample size. Exclusion of participants without English fluency.	52 patients focus groups and interviews	Negative impact of DCT on relationships, mobility, daily activities, finances, work, emotional wellbeing, changes in life

		of differentiated thyroid cancer (DTC) at different treatment phases.			and outlook on life.
'Good Cancer'.	(Easley, Miedema and Robinson, 2013)	It's the "Good" Cancer, So Who Cares? Perceived Lack of Support Among Young Thyroid Cancer Survivors.	Recruited via Facebook, one off telephone interviews. Self-referral bias.	12 patients, aged 18-39 at 1-5 years after treatment. Descriptive study.	There is a lack of support especially for young people. Big impact of cancer diagnosis even when prognosis is good.
Lived Experience.	(Misra <i>et al.</i> , 2013)	Patients' experiences following local-regional recurrence of thyroid cancer: A qualitative study.	Single centre, single contact study. Face to face interviews.	15 participants, semi-structured interviews	Significant effect on patients. Post-traumatic growth reported.
Disease impact on lives.	(Sawka <i>et al.</i> , 2009)	The impact of thyroid cancer and post-surgical radioactive iodine treatment on the lives of thyroid cancer survivors: A qualitative study.	Sample size based on data saturation, authors provided detailed description of methodology used.	16 participants, 3 focus groups, patients recruited from two centres. One of sessions. Qualitative, grounded theory.	Significant impact, fear and anxiety, some participants feel dismissed or confused about RAI.

**Appendix 2 Sample of Data Analysis**

	<b><u>LTS: Other mental symptoms</u></b>	<b><u>METS</u></b>	<b><u>SCAR</u></b>	<b><u>COVID-19</u></b>	<b><u>Psychological health ok</u></b>	<b><u>Psychological health bad</u></b>
NHS01		Yes- spine- removed in surgery	x-not bothered	Not that bothered	v	
NHS02	v-anxiety mood swings.		v-ok	No complains		v-improved but never recovered
NHS03			Not bothered	Happy had treatment before the pandemic. Not affected psychologically by COVID	v	
TC01	Anxiety, see longitudinal part.		ok	-more cautious, very careful,  -husband couldn't enter for RAI	Worry but coping well	Not bad but it is difficult, some days
TC02			v-healed nicely	v-had to self- isolate for 2 weeks before surgery and after.		

Appendix 3 Well-TC Study Protocol version 3.0



**STUDY PROTOCOL**

**FACTORS AFFECTING SUBJECTIVE WELLBEING AMONG PATIENTS  
DIAGNOSED WITH WELL-DIFFERENTIATED AND MEDULLARY THYROID  
CARCINOMA.**

**WELLBEING IN THYROID CANCER**

**Well-TC**

<b>Sponsor:</b>	<b>Northumbria University</b>
<b>Sponsor Ref:</b>	<b>13824</b>
<b>Funder:</b>	<b>Northumbria University and Butterfly Thyroid Cancer Trust</b>
<b>NHS REC ref:</b>	<b>19-NE-0175</b>
<b>IRAS</b>	<b>257474</b>
<b>NUTH R&amp;D</b>	<b>9055</b>
<b>Version and Date</b>	<b>3.0 Date 16.03.2020</b>

**This protocol has regard for the HRA guidance and order of content.**

**SIGNATURE PAGE**

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor

I also confirm that I will make the findings of the study publicly available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

**For and on behalf of the Study Sponsor:**

Signature:

Date:...../...../.....

.....

Name (please print):

.....Dr Jamie Harding.....

Position:....Principal Supervisor.....

**Chief Investigator:**

Signature:.....

Date:...../...../.....

Name: (please print):

.....Mrs Alicja Yilmaz.....

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## KEY STUDY CONTACTS

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Funder(s)	University of Northumbria in Newcastle Sutherland Building College Street Newcastle upon Tyne NE1 8ST  Butterfly Thyroid Cancer Trust, PO Box 205, Rowlands Gill, Tyne & Wear, NE39 2WX. Tel.01207 545469 enquiries@butterfly.org.uk

## STUDY SUMMARY

Study Title	Factors affecting wellbeing among thyroid cancer patients.
Internal ref. no. (or short title)	Well-TC (Wellbeing in Thyroid Cancer).
Study Design	Qualitative study, Descriptive Phenomenology.
Study Participants	Adults (over 18 years old) diagnosed with thyroid cancers: Papillary, Follicular or Medullary Thyroid Carcinoma.
Planned Size of Sample (if applicable)	Max 25 participants.
Follow up duration (if applicable)	No longer than October 2020
Planned Study Period	April 2019- September 2020 (18 months).
Research Question/Aim(s)	What are the factors affecting wellbeing of patients with thyroid carcinoma?

## FUNDING AND SUPPORT IN KIND

<b>FUNDER(S)</b> (Names and contact details of ALL organisations providing funding and/or support in kind for this study)	<b>FINANCIAL AND NON-FINANCIAL SUPPORT GIVEN</b>
Northumbria University	50% of Studentship Cost, Academic supervision
Butterfly Thyroid Cancer Trust	50% of Studentship Cost, Guidance
Newcastle Hospitals NHS Foundation Trust	Support with set up and recruitment

## **ROLE OF STUDY SPONSOR AND FUNDER**

Sponsor and co-founder Northumbria University: Academic Supervision, Legal Responsibility.  
Founder Butterfly Thyroid Cancer Trust: Limited study design advisory role, provision of PPI.  
Final decisions regarding any aspects of the study including study design, conduct, data analysis, interpretation, manuscript writing and dissemination of results lies with Chief Investigator Mrs Alicja Yilmaz.

## **PROTOCOL CONTRIBUTORS**

Academic supervision (Support in design, conduct, data analysis and interpretation, manuscript writing)

Principal Supervisor Dr Jamie Harding, Northumbria University

Second supervisor Dr Mark Cieslik, Northumbria University

Third supervisor Dr Annette Hand, Northumbria University

Fourth supervisor Dr Adele Irving, Northumbria University

### **KEY WORDS:**

Wellbeing, thyroid cancer, quality of life, thyroid cancer survivors, experiences of cancer, lived experience of disease.

### **STUDY FLOW CHART**

See appendix 4 page 17

## 1 BACKGROUND

Thyroid cancer is the most common thyroid neoplasia. Approximately 298000 new cases of thyroid cancer were diagnosed worldwide in 2012. In Europe, 53000 new cases of thyroid cancer were diagnosed in 2012. In the UK, there were 3528 new cases of this type of cancer in 2015, equivalent to nine every day. It is the 20th most common cancer type in men and the 17th in women (Cancer Research UK, 2018).

It has a high 5-year survival rate of 90% (Office of National Statistics, 2015). According to the above statistics, it is a comparatively uncommon and low-mortality cancer. However, according to Cancer Research UK (2018), its prevalence has more than doubled since the 1990s (148% increase) and in the last decade by 80%. It is predicted that it will rise by 74% in the UK by 2035. Thus, it is becoming more common.

Although this cancer has a high survival rate, the wellbeing of patients can be negatively affected (Gamper *et al*, 2015). The quality of life of people with thyroid cancer decreases 2 weeks post operation but it is back to normal state before the operation 6 months after the operation (Lubitz *et al*, 2016). The quality of life of patients has been compared to the quality of life of patients with more aggressive forms of cancer like colon, glioma or gynaecological cancer and the reason for it is currently unknown (Applewhite *et al*, 2016). About a fifth of all patients have a recurrence of the disease most of which happen in the first few years following the initial prognosis. For some patients however, it can take few decades for the disease to recur (Grogan *et al*). Thus, lifelong follow up is necessary to monitor the disease and repeat the treatment if necessary (Lubitz *et al*, 2016).

Some factors that may affect wellbeing of people with thyroid cancer are uncertainty about outcomes, separation from children (Harding, 2016), quality of surgery (Brabus *et al* 2017) or not being taken seriously (Sawka *et al*, 2009). However, as previously stated, these are results of quantitative studies only. Moreover, those studies differ in the method chosen and concept of quality of life as opposed to wellbeing.

This study will use qualitative, in-depth interviews to establish factors that affect patients with thyroid cancer. The study has two aspects: longitudinal and retrospective. The population eligible are patients diagnosed with papillary, follicular or medullary thyroid carcinoma. In longitudinal part of the study, each participant will be asked to participate in 3 in-depth interviews about their cancer experiences and how it affects their everyday life and experiences. They will be given a paper journal or advised to use any journal-type application/programme for electronic device of choice. In the retrospective side of the study, retrospective interviews will take place with thyroid cancer survivors.

The researcher is interested in looking at changes in wellbeing in different times during and following treatment. Moreover, the researcher will look at factors across all areas of life that may affect wellbeing following thyroid cancer diagnosis in order to explore why the quality of life is so poor in thyroid cancer, as well as meeting other study objectives.

## **2 RATIONALE**

As shown above, a cancer diagnosis can induce a decline in the patient's quality of life. Patients diagnosed with thyroid cancer experience significantly decreased quality of life and potentially decreased wellbeing. Thyroid cancer has high survival rate but also high recurrence rate and patients in most cases are going to be having lifelong follow up. Thyroid cancer diagnosis including its treatment and follow ups has a big impact on people as showed by Bărbuş *et al*, (2017). In their literature review the researchers included studies that looked mostly at quality of life in patients with different treatment options for thyroid cancer (Sawka *et al* 2009, Nygaard *et al* 2013, Rubic *et al* 2014, Jeong *et al* 2015, Vega-Vasquez *et al* 2015, Gamper *et al* 2015). These researchers used quality of life questionnaires, apart from Sawka *et al* (2009) who used focus groups to explore the impact of thyroid cancer on quality of life. Thus, there is a lack of qualitative evidence and the lack of proposed explanation for decreased quality of life. The research will help clinicians to address these issues and develop interventions that would support patients through thyroid cancer diagnosis, treatment and beyond. There is evidence of existing interventions that help patients with cancer such as Cognitive Behavioural Therapy, psychosocial intervention and stress management (Lutgendorf and Anderson, 2015). However, according to Morley and Goldfarb (2015) and Gamper *et al* (2015) more qualitative research is needed to define the unmet needs of patients with thyroid cancer and to identify interventions with evidence-based benefits

### **2.1 Future benefits for NHS and patients**

This proposed study will improve our understanding of interconnections between health and wellbeing. This is an important topic, as wellbeing is a building block of mental health that determine the quality of life. This study would fill the gap in current knowledge by conducting qualitative research looking at the wellbeing of patients with thyroid cancer. The results may be used to improve the services provided for patients and improve understanding amongst health care professionals and charities about patients' needs with potential long-term benefits for patients. It is particularly important for care team including nurses (Miller, 2010). Furthermore, the results of this study may be used to create comparison between those patients receiving different treatments. This will be helpful in evaluating service provision and making recommendations for service development. Qualitative data enhances health care professionals' understanding of experiences of their patients and can assists in planning of care and providing supportive, person-centred compassionate care. This research will also provide a list of

recommendations for practice and support, based on participants' suggestions and needs. Patient group may benefit from the study as care team will improve the understanding of the needs of patients which can turn to more person-centred care (Addo and Eboh, 2014). Knowledge about their needs and proposed solutions will be generated. Based on this new knowledge there is a potential that interventions may be developed to improve lives of people affected by thyroid cancer. This new knowledge will also allow clinicians and researchers to concentrate their interventions development as well as research to those main issues.

The main potential impact is improvement in the wellbeing of patients with thyroid cancer and providing directions for future research within the NHS.

### **3 PARADIGM**

Qualitative methodology was used for this study to address the question of what factors affect patients with thyroid cancer. Qualitative research allows the investigation and exploration of patient lived experiences and factors that affect those experiences. Qualitative enquiry can help in answering question of why quality of life is affected (Gelling, 2015). The researcher in this study wants to find out why the quality of life of people is comparable to the quality of life of patients with more deadly and invasive forms of cancers. Qualitative enquiry using phenomenological study design is the method that will be used to explore wellbeing as it gives a subjective point of view of people directly affected by the disease (Todres and Hollow, 2010).

Phenomenology derived from the writing of German philosophers Edmund Husserl and Martin Heidegger (Gelling, 2015). The researcher chosen descriptive phenomenology as opposed to interpretative phenomenology. Descriptive phenomenology is, an objective approach using "phenomenological approach" where "Bracketing" is a method of putting aside pre-existed assumptions of the researcher. As such the results will give a direct voice to participants about the meanings they attach to their experience as well as how it affects their wellbeing.

Phenomenological enquiry is interested in establishing an essence of the experience in order to understand the phenomenon in interest (Sokolowski, 2010).

In order to conduct valuable research with a potential to directly help patients, by exploring the needs of patients with thyroid cancer, the researcher will concentrate on factors that affect their wellbeing. According to Pinto and Martins (2017) wellbeing is a psycho-spiritual state, similar to happiness. Some authors even use wellbeing interchangeably with happiness (Cieslik, 2015). This can be explained by the definition of wellbeing as "a state of being comfortable, healthy or happy" (Oxford dictionaries, 2018). The reason why the researcher chose wellbeing over quality of life is that she would like to go beyond changes in quality of life and explore factors affecting psychological wellbeing even if quality of life remains the same. For example, employment situation may not change following the diagnosis of thyroid cancer (Tamminga *et al*, 2015) but patients may still experience worry and fear about work-related issues (Harding, 2016) and as

such, their wellbeing will be affected. Kiefer (2008) states that wellbeing is affected by physical, mental, social and environmental factors. In this study, the researcher will look at factors across all areas of life that may affect wellbeing following thyroid cancer diagnosis in order to achieve the project's objectives.

#### **4 RESEARCH QUESTION / AIM(S)**

To explore factors affecting wellbeing among adults diagnosed with thyroid cancer.

##### **4.1 Objectives**

1. To explore factors that affect the wellbeing of patients during and after treatment for thyroid cancer.
2. To explore specifically the impact of hospital care and treatment.
3. To devise framework of changes to these factors in time.

##### **4.2 Outcome**

Knowledge of factors that affect wellbeing of adults with thyroid cancer. Increasing understanding of the reason why the quality of life of patients is comparatively low. The results may be used to improve the services provided for patients and improve understanding amongst health care professionals and charities about patients' needs with potential long-term benefits for patients. Furthermore, the results of this study may be used compare the experiences between patients receiving different treatments. This will be helpful in evaluating service provision and making recommendations for service development.

#### **5 STUDY DESIGN and METHODS of DATA COLLECTION AND DATA ANALYSIS**

##### **5.1 Study design**

The qualitative phenomenological study approach will be used. Phenomenology is used to explore lived experience and their meaning (Polit and Beck, 2010). It enables the researcher to gain understanding of the social reality of people studied (Grey, 2009). The study has two elements, one prospective longitudinal and one retrospective longitudinal. In the longitudinal aspect of the study, it will follow patients through their journey through treatment and recovery. In retrospective element, interviews with thyroid cancer survivors will take place, the

participants will be asked to look back on their experiences with thyroid cancer through different stages.

## **5.2 Data collection methods:**

Prospective Longitudinal Interviews: In-depth semi-structured face to face or telephone interviews with cancer patients. Placed in the participant's home or other suitable place of their choice. The interview guide will be used to make sure all main topics are covered. Interviews will be audio-recorded.

Retrospective Longitudinal Interviews: In-depth semi-structured face to face interviews with cancer patients. Placed in the participant's home or other suitable place of their choice. The interview guide will be used to make sure all main topics are covered. Interviews will be audio-recorded.

Diaries: paper journals will be handed out to willing cancer patients (longitudinal participants) to record a reflective account of their treatment and experiences. Patients will also have the option of using a journal application on their electronic device (mobile phone/ tablet), web journal (online) or audio journals (YouTube, short videos on the phone).

## **5.4 Data analysis**

The researcher have chosen a Giorgi, 1985 method of phenomenological data analysis. It provides a robust and systematic approach to data analysis (Wirihana *et al*, 2018). The data will be grouped in themes in order to interpret and describe the phenomena. The data from interviews will be supplemented by data from diaries where available. Data from diaries may provide more detailed insight to participants lived experiences.

The researcher will use a computer programme to code and theme qualitative data NVivo, due to the fact that it makes data analysis faster and more flexible (Bazeley, 2013).

While analysing data, the researcher will try to extract what are the factors that may affect the wellbeing of participants. After subsequent interviews the researcher will try to establish if the factors are changing and whether new once are emerging.

## 5.5 Schedule of procedures

### Prospective Longitudinal participants

1. Identification of potential participant. Thyroid Cancer CNS will introduce patients to the study by providing them with a “Potential Participants Information Pack” that includes study leaflet, PIS and consent to contact in a pre-paid envelope. This will happen in one of their standard care appointments.

2. First contact with researcher. Potential participants interested in the study will either contact the researcher directly or alternatively they will sign and send the consent to contact to the researcher. During the first telephone or email conversation, potential participants will be able to ask questions, gain more detailed knowledge about the study. Willing potential participants will be invited for an initial appointment. It will be arranged in a suitable time and place for participants and the study (for example, participant’s home, University or Freeman Hospital). Pre-screening questions include:

- Clinical information: diagnosis and treatment pathway.
- Personal information: marital status, kids, employment situation.

3. Initial appointment. At the initial meeting or telephone consultation, participants will be able to ask any questions they may have. Detail description of the study will be provided. The researcher will go through consent form explaining the meaning of each statement. When the informed consent is signed, the patient will be asked few demographic and social questions as well as their diagnosis and treatment pathway. Then the researcher will start the interview according to the attached guide.

4. Handing out Diaries. During this first meeting, patients interested and consented to completing a diary, will be handed a paper diary with printed instruction on the first page.

Date and time of next appointment may be discussed.

5. Confirming diagnosis and treatment with health care professionals. After the initial interview, the researcher will confirm the diagnosis and treatment pathway by asking a health care provider (most likely Thyroid Cancer CSN) to fill in the medical information request form.

6. Second Interview. The researcher will either contact the participant or the visit will be booked at previous contact. The researcher will conduct a follow up interview according to follow up interview guide.

If this is a final appointment, patients will be asked to hand in the diary to the researcher.

7. Third Interview. The researcher will either contact the participant or the visit will be booked at previous contact. The researcher will conduct a third interview according to follow up interview guide.

8. Collecting Diaries. Patients will be asked to hand in the diary to the researcher.

7. Data analysis check. After data collection finishes, patients may be asked (by email) to confirm the validity of the researcher analysis.

### **Retrospective Longitudinal part of the study:**

1. Identification of potential participant. Thyroid Cancer CNS will introduce patients to the study by providing them with a “Potential Participants Information Pack” that includes study leaflet, PIS and consent to contact in a pre-paid envelope. This will happen in one of their standard care appointments.

2. First contact with researcher. Potential participants interested in the study will either contact the researcher directly or alternatively they will sign and send the consent to contact to the researcher. During the first telephone or email conversation, potential participants will be able to ask questions, gain more detailed knowledge about the study. Willing potential participants will be invited for an initial appointment. It will be arranged in a suitable time and place for participants and the study (for example, participant’s home, University or Freeman Hospital). Pre-screening questions include:

- Clinical information: diagnosis and treatment pathway.

- Personal information: marital status, kids, employment situation.

3. Initial appointment. At the initial meeting or telephone consultation, participants will be able to ask any questions they may have. Detail description of the study will be provided. The researcher will go through consent form explaining the meaning of each statement. When the informed consent is signed, the patient will be asked few demographic and social questions as well as their diagnosis and treatment pathway. Then the researcher will start the interview according to the attached guide.

4. Confirming diagnosis and treatment with health care professionals. After the initial interview, the researcher will confirm the diagnosis and treatment pathway by asking a health care provider (most likely Thyroid Cancer CSN) to fill in the medical information request form.

5. Data analysis check. After data collection finishes, patients may be asked (by email) to confirm the validity of the researcher analysis.

## **6 STUDY SETTING**

It is a single centre study. The site is a local centre of treatment of the disease in question (Northern Centre for Cancer Care, Freeman Hospital, Newcastle Hospitals NHS Foundation Trust). The setting will provide initial access to the sample and possible site for the interviews and focus groups as well as advertising site (posters, leaflets).

## **7 SAMPLE AND RECRUITMENT**

### **7.1 Eligibility criteria**

Study population includes adults (over 18) with a preferably recent diagnosis of well-differentiated thyroid carcinoma (papillary, Follicular and Medullary). Patients that will not be eligible are diagnosed with a terminal thyroid cancer, different type of terminal cancer and Anaplastic Thyroid Carcinoma. This is due to the fact that the life expectancy is short, thus the wellbeing of patients will be significantly different. Moreover, the research would like to concentrate on thyroid cancer as an episode in life and then eventually a part of life and its effects on overall wellbeing.

#### **7.1.1 Inclusion criteria**

##### **Prospective Longitudinal participants:**

1. Adults (over 18).
2. Patients with Diagnosis of papillary, Follicular or Medullary Thyroid Cancer within 8 weeks of diagnosis (**or more than 8 weeks if treatment has not yet started**).
3. Able to give informed consent.

##### **Retrospective longitudinal participants:**

1. Adults (over 18).
2. Patients with Diagnosis of papillary, Follicular or Medullary Thyroid Cancer within 5 years of diagnosis.
3. Able to give informed consent.

#### **7.1.2 Exclusion criteria for both prospective and retrospective participants.**

1. Diagnosis of Anaplastic Thyroid Cancer
2. Diagnosis of Terminal Thyroid Cancer

### 3. Co-diagnosis of different than thyroid terminal cancer

## 7.2 Sampling

Sampling: Purposeful Quota Sample of maximum variation adults diagnosed with thyroid carcinoma (papillary, Follicular, Medullary). This is an optimal sample and in practice this may be difficult to achieve as some pathways are more common than others.

- 4 Participants with Treatment option 1 (Partial thyroidectomy)
- 4 Participants with Treatment option 2 (Total thyroidectomy)
- 4 Participants with Treatment option 3 (Total thyroidectomy and RAI)
- 4 Participants with Treatment option 4 (Total Thyroidectomy, Neck dissection and RAI)
- 4 Participants with Treatment option 5 (Medullary cancer, surgery and chemotherapy)
- 4 Participants 1-5 years post-diagnosis.

The researcher would like at least 25% of participants to be working parents in order to explore added pressure of cancer diagnosis of people juggling both family and work commitments.

### 7.2.1 Size of sample

Recruitment of participants will be carried out until the optimum sample size is reached and sample is varied and representative of some different treatment pathways and social categories. The researcher is planning to recruit at least 12 patients and set a limit of maximum 24 participants. This is a relatively large sample for phenomenological study, however, this will allow the researcher to investigate and compare experiences of different treatment pathways and social groups for example, working parents experience compared to single people experience.

### 7.2.2 Sampling technique

Purposive “quota” sample technique will be used in order to include variety of clinical treatment pathways and social categories of people, especially regarding to employment, parenthood and relationship. The sample strategy reflects the aims of the project.

## **7.3 Recruitment**

### **7.3.1 Sample identification**

Initial identification will be made by the Thyroid Cancer Clinical Nurse Specialist. Potential participants will be given potential participant information pack which includes: information leaflet, Patient Information Sheet and Consent to Contact. The patient will then make a choice if they would like to be contacted. They can send a consent to contact form in a pre-paid envelopes and send it to the researcher. Alternatively, they can contact the researcher by phone or email without the need of filling the consent to contact. The researcher will then contact potential participants. In case of difficulty with recruitment, the researcher will seek support from Butterfly Thyroid Cancer Trust (BTCT) with recruitment through advertising of the study on their website as well as leaflets and posters in the study NHS setting. At first all eligible participants will be recruited. Later during the recruitment process the researcher will be more selective in which participants will take part in order to create a varied sample of treatment pathways and social category.

In situation, when the recruitment of newly diagnosed patients proves to be difficult, the researcher will seek to recruit thyroid cancer survivors, patients that were diagnosed 1-5 years ago.

Potential resources used: consent to contact, Patient Information Sheet, advertisement through BTCT website, posters and leaflets in the hospital area.

Participants will not receive any payment or incentives for their voluntary contribution apart from refreshments and snacks provided by the researcher during the interview process. If participants do not wish to have their interview in the house, they can be reimbursed travel expenses (Public Transport and petrol, but no taxi fare).

### **7.3.2 Consent**

At prospective patient identification point (with the Thyroid Cancer Specialist Nurse) patients will be given Patient Information Sheet (PIS) or consent to contact. If patients will choose to give consent to contact the researcher will contact them and after their verbal consent will send them the PIS to their home address. The consent will be sought minimum 24 hours from the moment that PIS is given in order to give potential participants time to consider their participation. There will be an opportunity to ask question and change their mind about taking part in the study at any time.

At initial appointment the capacity of potential participant will be assessed. The discussion will cover all points of consent form as well as description and rationale of the study. All questions will be answered. All risk and the benefits of the participation will be disclosed. The voluntary nature of the participation will be emphasised.

## **8 Ethical considerations**

This is a non-therapeutic non-intervention study. It is high risk due to the fact that the participants are NHS patients. The risks include disclosing safeguarding information, distress, time-consuming and tiring interviews and talking about sensitive issues with a stranger. The benefits of the participation include the opportunity to take part in research study, opportunity to express their emotions and explore their experiences, opportunity to have their experiences validated, and opportunity to potentially help others. The patients may be considered as vulnerable as they have recently received a cancer diagnosis. The researcher will respect confidentiality and dignity of participants at all time. The study gained approved of Northumbria University Ethical Committee as well as NHS REC Committee.

### **8.1 Assessment and management of risk**

Patients may disclose safeguarding information to the researcher. The researcher will act in the best interest of the participant and other peoples affected. The researcher will act according to their professional knowledge and code of conduct of the nursing profession provided by the NMC (Nursing and Midwifery Council). As part of a consent form, the participant will consent to the possibility that the confidentiality may be breached in a situation when there is a possibility of harm to the participant or others.

Interviews:

They are time-consuming and may be tiring. Participants have to allocate up to 2 hours each time. They may have to adopt with their plans for the day and it may be inconvenient. To minimise it, participants will be asked about best place, time and date for the meeting. Also, the participants will be reassured that they can stop the interview or cancel or rebook it at their convenience. The interview can be also completed in two parts if the participants prefers shorter interviews.

Participants may be uncomfortable inviting stranger to their home and may feel pressure to take part if the researcher has travelled to their location. To minimise it, participants will be given an option to have the meeting at their home, Freeman Hospital or any convenient location for them.

Participants may become upset or distressed when talking about their lives and cancer. It is highly likely that this may happen with some participants. The researcher is a nurse with many years of clinical experience as well as additional training in counselling. The researcher will provide support and reassurance within their competencies and professional boundaries. Moreover, leaflet with information explaining where they can access extra support if needed be, will be provided. They will also be reassured that they may stop the interview at any point, withdraw from the study or avoid upsetting topics if they so wish.

Participants may become uncomfortable talking about certain aspects of their life. Participants will be reassured that they do not have to say anything that they are not comfortable with.

Diaries:

Participants may feel obliged to complete diaries even though they don't really want to. The researcher will emphasise that it is voluntary.

Diaries are time-consuming and require self-reflection that can be painful or distressing. I will emphasise that the diaries are not mandatory and they can still participate in interviews and not in keeping diaries. I will make sure that only participants who really like to keep diaries will be given this option.

## **8.2 Research Ethics Committee (REC) and other Regulatory review & reports**

The study gained an approval from NHS REC Committee. The management of the study will comply with the regulations from the NHS REC.

## **8.3 Regulatory review & compliance**

The study is approved by the R&D department of the Newcastle Hospital NHS Foundation Trust which is the only NHS site of the study.

## **8.4 Amendments**

### **8.5**

All amendments will be dealt with according to HRA guidance as well as Northumbria University guidelines. Substantial amendments will be dealt with by submitting a valid notice of the amendment to the REC for consideration. The R&D department of the NUTH will also be informed by mail. The responsibility of the management of the study including amendments lie in the researcher, Alicja Yilmaz. The history of amendments and all versions of the study protocol and documents will be held in study master file. The numbering of protocol will reveal

the current version of the protocol for example initial version 1.0 then 2.0. The history of amendments will be provided in the appendix of the protocol.

## **8.6 Peer review**

The study has been reviewed by a Panel of three Academics at Project Approval meeting at Northumbria University.

## **8.6 Patient & public involvement**

The researcher sought Patient and Public involvement early in the design process of the study.

- PhD students at Northumbria University PGR seminar
- Thyroid Cancer Medical Clinicians from NUTH (Newcastle Hospitals NHS Foundation Trust)
- Thyroid Cancer Nurse Specialist from NUTH
- Staff of Butterfly Thyroid Cancer Trust
- Two patients with thyroid cancer, one current and one survivor of thyroid cancer
- Research Nurse from NIHR CRN North East and North Cumbria.

The researcher asked questions regarding to readability, volubility and reasonability of the study design and documents like PIS and consent form.

## **8.7 Protocol compliance**

Protocol breaches and deviations will be reported to academic supervisor and if necessary to the R&D department of the NUTH.

## **8.8 Data protection and patient confidentiality**

Patient confidentiality and data protection will be safeguarded and managed in accordance to rules in GCP and requirements of the Data Protection Act 2018 as well as General Data Protection Regulations (GDPR). The identifiable patient data will be securely stored in secured

U drive (Northumbria University) in a password protected word or excel file. Participant confidentiality will be maintained by anonymising data using a study participant's identification number AY01, AY02, AY03.

Individual participant's medical information obtained as a result of this project will be considered confidential and the access is prohibited by third parties. The only person to have access to identifiable data as well as limited medical information is the researcher Alicja Yilmaz. Pseudorandomised data sets will be stored securely for 7 years. Identifiable data will be stored for 12 months after the data analysis is completed (March 2021). Data custodian is the researcher Alicja Yilmaz.

Data that will be generated in this study will be available for inspection on request from University of Northumbria representatives, the NHS REC and study site R&D Department.

## **8.9 Indemnity**

Indemnity insurance is in place from the sponsor Northumbria University.

## **8.10 Access to the final study dataset**

Anonymised data that will be generated in this study will be available for inspection on request from University of Northumbria representatives, the NHS REC and study site R&D Department.

## **8.11 Limitation of the study**

Limitation of the study includes a single setting for recruitment. It is due time constrain of a PhD Studentship.

Moreover, due to the same reason, some patients may not be able to have their final interview. However, the researcher will still be able to meet the research objectives.

# **9 DISSEMINATION POLICY**

## **9.1 Dissemination policy**

The results of this project will be disseminated in peer-reviewed journals and scientific events. Participants will not be named in any published or unpublished dissemination writings, nor will any identifying information be revealed.

The completed PhD thesis will be available through the Northumbria University Research Link website.

The Butterfly Thyroid Cancer Trust will be acknowledged within publication as the funding body.

Participants will be able to contact the researcher at any point in the future and request copy of data in a form of published journal article or unpublished dissemination in a form of presentation. They will also be able to access the entire thesis from the Northumbria University website. The participants will be informed about the time when the data will be disseminated on the website of Butterfly Thyroid Cancer Trust.

## **9.2. Authorship eligibility guidelines and any intended use of professional writers**

The authorship on the final study report will be granted to Alicja Yilmaz.

### **PROTOCOL REFERENCES**

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## 11. APPENDICES

### 11.1 Appendix 1- Required documentation

Consent Form, Patient Information Sheet, Enrolment log, Copy of recruitment website post. Poster, Protocol, Form for care team, Consent to contact, Interview guide, Diary guide.

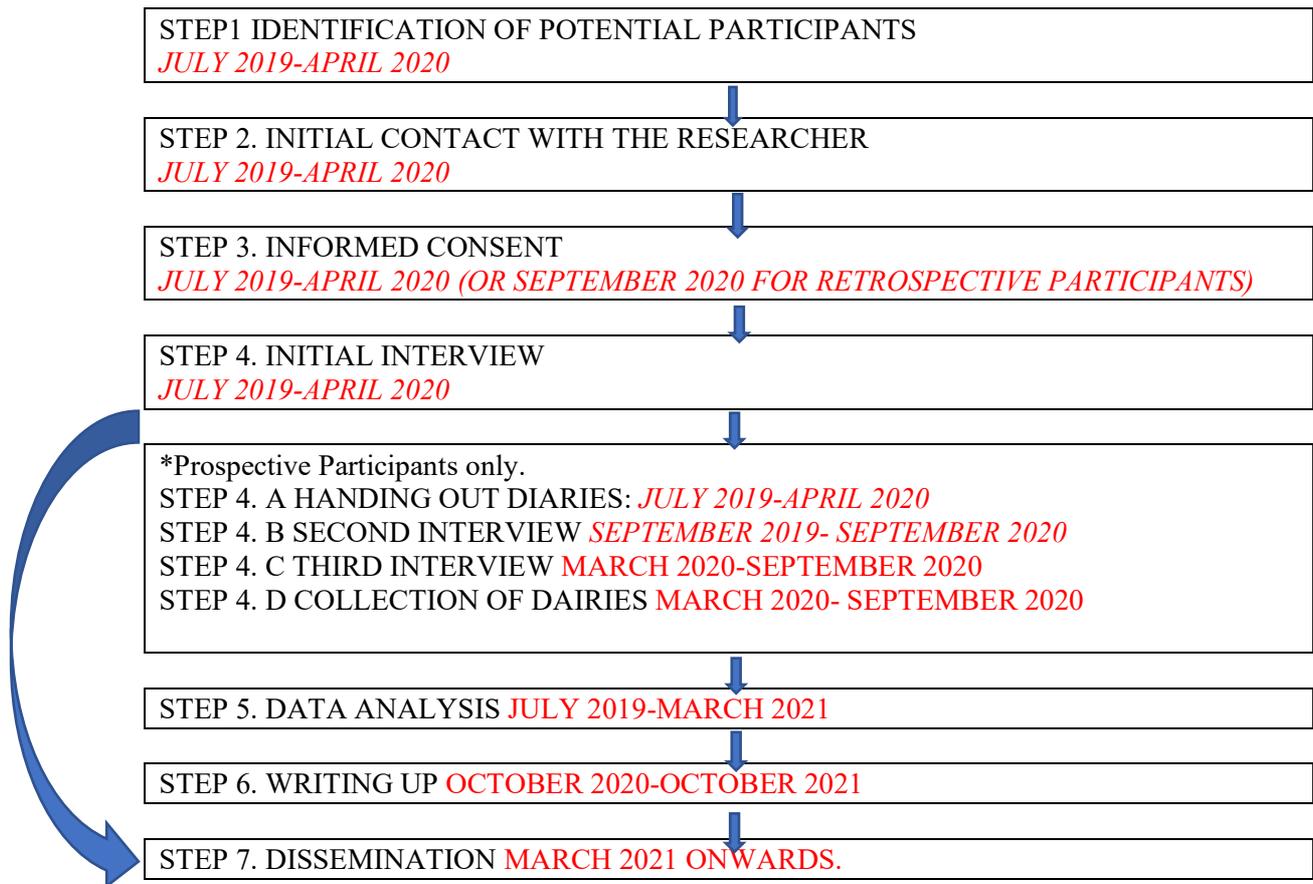
### 11.2 Appendix 2 – Schedule of procedures

Procedures	Timeline				
	Identification of potential participants	Initial contact with researcher (0-1 month)	First interview (0-1 month)	<u>For prospective longitudinal only.</u> Second interview 2-6 month from diagnosis	<u>For prospective longitudinal only.</u> Third interview 6-12 months post-diagnosis
Consent to contact or PIS given	x				
Screening form		x			
Informed Consent			x		
Interview			x	x	x
Diary-hand out			x		
Diary-collection					x

### 11.3 Appendix 3 – Amendment History

Amendment no.	Protocol version no.	Date issued	Author(s) of changes	Details of changes made
1	2.0	15.11.2019	Alicja Yilmaz	Widening inclusion criteria.
2	3.0	16.03.2020	Alicja Yilmaz	Adding telephone interviews to data collection methods.

#### 11.4 Appendix 4 – Study Flow Chart



## Appendix 4 Invitation letter



### The Newcastle upon Tyne Hospitals NHS Foundation Trust

Dear Sir/Madame,

You have been invited to take part in a new study, supported by Newcastle upon Tyne NHS Foundation Trust and the Butterfly Thyroid Cancer Trust.

The eligible potential participants will be over 18 years old and, in the last 5 years, diagnosed with papillary, Follicular or Medullary Cancer. Each participant will be asked to undertake a maximum 3 interviews.

The study is looking into wellbeing and changes in wellbeing in time as well as factors affecting wellbeing during and after diagnosis. The study has the potential to contribute to the body of knowledge regarding wellbeing in thyroid cancer as well as helping to shape future research into interventions designed to help people in this situation.

If you are interested in taking part in this study, please read attached Participant Information Sheet or contact Alicja Yilmaz for more information:

[alicja.yilmaz@northumbria.ac.uk](mailto:alicja.yilmaz@northumbria.ac.uk)

Tel: 07746312415

Project partially funded by Butterfly Thyroid Cancer Trust- a registered Thyroid Cancer Charity.

**Appendix 5**

**CONSENT TO CONTACT**

Project title: Factors affecting wellbeing of thyroid cancer patients / Well-TC

Researcher: Alicja Yilmaz

I agree to be contacted by **telephone/ email** (circle your preferred option) by the researcher Alicja Yilmaz with regard to potential participation in the Well-TC study

*please initiate  
the box*

My telephone number:.....

My email address .....

Signature of POTENTIAL participant.....Date.....

(NAME IN BLOCK LETTERS).....

To be completed by the researcher:

Signature of Researcher/Health Professional.....Date.....

(NAME IN BLOCK LETTERS).....

## Appendix 6

### PARTICIPANT INFORMATION SHEET

**Name of Researcher: ALICJA YILMAZ**

**Name of Supervisor: DR JAMIE HARDING**

**Project Title:**

#### **FACTORS AFFECTING WELLBEING AMONG THYROID CANCER PATIENTS.**

**We would like to invite you to take part in this PhD research project. Please read the Participant Information Sheet and take as much time as you need before making the decision. The researcher will answer any questions that you may have.**

#### **1. What is the purpose of the project?**

*The purpose of this study is to explore wellbeing of patients with thyroid cancer and factors that affect their wellbeing during and after treatment.*

#### **2. Why have I been invited?**

*You have been invited to take part in the study as you had been diagnosed with Papillary, Follicular or Medullary Thyroid Carcinoma, either recently or in the past.*

#### **3. Do I have to take part?**

*No, it is completely your decision to decide whether you would like to take part in this project. The researcher will provide you with all the information necessary to make an informed decision. If you agree to take part you will be asked to sign a consent form. You will receive a copy of it for your records. If you do not wish to take part in the study, your care will not be affected in any way. If you decide to take part, you can withdraw from the study at any time.*

#### **4. What is involved?**

*The thyroid cancer prognosis is considered to be excellent. However, the literature shows that the quality of life of patients is often affected in a similar way to that of patients with more malignant cancers like breast or lung cancer. This study will explore the possible reasons for this. Moreover, the specifics of thyroid cancer mean that patients often face life –long follow ups. This can have further implications for their wellbeing. This study will explore these topics to further our understanding of the needs of patients with thyroid cancer. The knowledge gained should also allow us to create more informed interventions in order to help the cancer patients and cancer survivors.*

*The study has been set up to recruit approximately 12 to 24 patients in different points of their treatment and recovery journey. Patients will be asked to participate in interviews. Willing*

*participants can also complete a paper journal (mobile and online journal option are also possible) where they can record their feelings, experiences and reflections. This data will then be analysed. Common themes will be identified from participants' stories that will allow us to improve understanding of the phenomenon of living with and beyond thyroid cancer.*

*Analysed data will be published in journals and presented at scientific events. Any identifiable information and data will not be published.*

#### **5. What would taking part involved?**

*If you decide to contact or to be contacted by the researcher, you will be asked a few screening questions. For example, you will be asked about your diagnosis and treatment. This is to establish, if you are eligible to take part. You may also be asked your age, marital and employment status and whether you have any children. The reason is, that the researcher is looking to interview participants with different life circumstances.*

*After an informed consent process, you will be asked to answer a few questions conforming your screening questions information and details of your diagnosis. This will be in a form of a short questionnaires that you will fill in together with the researcher.*

*You will be asked to participate in in-depth face to face or telephone interview(s) with the researcher. The interviews will last up to 2 hours and can happen in your home, Northumbria University (Coach Lane Campus or City Campus) or Freeman Hospital depending on your preference.*

*You may be asked if you are willing to see the researcher again for a second interview (maximum of three interviews per participant), depending on where you are in your treatment journey. The consequent interviews will be much shorter, lasting about an hour.*

*The whole data collection process will take a maximum of 18 months from first to last interview (maximum 3 in total), however for the majority of participants it will be a shorter time period.*

*Participants, who have completed their treatment in the past (1-5 years) will only be interviewed once.*

*If it is appropriate, you may also be asked to keep a diary where you can report your experiences.*

*This is optional. You can still take part in the interviews and choose not to keep a journal/diary. Diaries will be provided by the researcher in the form of a paper notebook. You can also use any suitable mobile or online application. Agreed parts of completed diaries will be collected at the last scheduled interview. They will be handed back to you after transcribing.*

*You can fill the diary with your experiences and reflections regarding thyroid cancer and how it affects your life (living with the disease, treatment, family, work, social life etc.). If you choose to keep a diary, more detailed guide will be provided.*

#### **6. What are the possible benefits of taking part?**

*There is no direct benefit to yourself from taking part in this study. However, by taking part you may help other people with thyroid cancer in the future. The results may be used to improve the services provided for patients and enhance understanding amongst health care professionals and charities about patients' need. This has potential long-term benefits for future patients. You will be provided with a copy of the study results after the completion of the study.*

#### **7. What are the possible disadvantages and risks of taking part?**

*This is a non-interventional study. You will be asked questions about sensitive topics such as being diagnosed with cancer. However, you don't have to answer any question that you are uncomfortable with. You can also withdraw from the study at any point. The researcher will provide information about support available for cancer patients that may be helpful in coping with the psychological effects of the treatment and the diagnosis. Moreover, contact details will be provided for a thyroid cancer clinician in case you would become distress as a result of the study.*

**8. What will happen if I don't want to carry on with the study?**

*You can withdraw from the study at any time without giving a reason. If you wish, the data that you have already provided can still be used in the study. If you wish to withdraw your data from the study, then you can simply email the investigator named in the information sheet and given them the code number that was allocated to you (for example AYXX).*

*There are no consequences of withdrawal from the study as your participation is voluntary. The medical and social care that you receive will not be affected.*

**9. Expenses and Payments?**

*We do not anticipate that participation in this study will create any expenses for you. If you prefer to have your interviews in any other place than your home, travel expenses (Public transport and petrol) can be reimbursed. Please note that if you choose to travel by taxi, the fare will not be reimbursed.*

**10. Who is organising and funding of this study?**

*The research is sponsored by Northumbria University. It is funded by Northumbria University and Butterfly Thyroid Cancer Trust. This research project is a partial requirement for a degree of Doctor of Philosophy.*

**11. Who has reviewed the study?**

*This research has been reviewed by the Northumbria University Research Ethics Committee as well as NHS Research Ethics Committee. The study has been approved by R&D Department of Newcastle Hospitals NHS Foundation Trust.*

*IRAS ref: 257474*

*NUTH R&D number: 9055*

*Northumbria University study Number: 13824*

**12. What to do next?**

*You can contact Alicja on 07746312415*

*Or email [alicja.yilmaz@northumbria.ac.uk](mailto:alicja.yilmaz@northumbria.ac.uk)*

*Or fill in the consent to contact and send it in attached pre-paid envelope, then the researcher will get in touch with you. This conversation will not be obliging. All your questions will be answered. Then you can decide if you would like to book a consent visit.*

***University of Northumbria at Newcastle is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. University of Northumbria at Newcastle will keep identifiable information about you for 1 year after the study has finished.***

***Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already***

*obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.*

*You can find out more about how we use your information at [here](#):*

*<https://www.hra.nhs.uk/information-about-patients/>*

*The researcher will keep your name, age and contact details confidential and will not pass this information to University of Northumbria. The researcher will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from University of Northumbria and regulatory organisations may look at your medical and research records to check the accuracy of the research study. University of Northumbria will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name, or contact details.*

*The researcher will keep identifiable information about you from this study for 1 year after the study has finished.*

*This study and its protocol have received full ethical approval from Faculty Art Design and social Science and Northumbria University Research Ethics Committee. If you require confirmation of this, or if you have any concerns or worries concerning this research, or if you wish to register a complaint, please contact the Chair of this Committee Dr Mary Laing stating the title of the research project and the name of the researcher.*

*If interested, please contact Alicja at [alicja.vilmaz@northumbria.ac.uk](mailto:alicja.vilmaz@northumbria.ac.uk)  
Tel: 077463124xx*

## Appendix 7

### CONSENT FORM

#### FOR ALL PARTICIPANTS

Project title: Factors affecting wellbeing among thyroid cancer patients.

Researcher: Alicja Yilmaz

Please read carefully and put your initials in the provided boxes. Please sign both copies and retain one of them for your records.

*please initials  
boxes*

I confirmed that I have had sufficient time to carefully read and understood the Participant Information Sheet version.....dated.....

I have had an opportunity to ask questions and discuss this study and I have received satisfactory answers.

I understand I am free to withdraw from the study at any time, without having to give a reason for withdrawing, and without my medical or legal rights being affected.

I agree to take part in this study.

I understand that I will participate in one (for Retrospective interviews) or a series of (maximum 3) interviews that will be audio-recorded and that only the researcher will have access to the recording.

I understand that I will be contacted by the researcher by telephone or email to organise the initial and follow up interviews.

I understand that I can choose not to answer any question in the interview where this is my preference

I understand that all information provided by me will be kept anonymous EXCEPT in cases where safeguarding is an issue.

I understand that study information about and the copy of signed consent form will be held at Northumbria University in accordance with the UK Data Protection Act 2018 and European General Data Protection Regulations (GDPR). I understand that this data will be kept strictly confidential and no personal information will be used in any publications.

I understand that in case of using an interpreter and translation services, all study data I have provided will be listened to and read by those services.

I understand that data that will be generated in this study will be available for inspection on request from University of Northumbria representatives, the NHS REC and study site R&D Department.

I agree that my direct quotes may be published in journal articles and presented at scientific events.

FOR PARTICIPANTS WHO WILL BE COMPLETING DIARY

*Diary will be return to you after transcription.*

I agree to deposit **the whole/an agreed portion of my diary** with the researcher by an agreed date, in order to transcribe it.

I agree that my **diary/an agreed portion of my diary** will be read, transcribed and analysed by the researcher.

I agree that my direct quotes may be published in journal articles and presented at scientific events.

Signature of participant..... Date.....

(NAME IN BLOCK LETTERS).....

Signature of researcher..... Date.....

(NAME IN BLOCK LETTERS).....

## Appendix 8

Dear Thyroid Cancer Care Provider,

I am writing to inform you that Mr/Mrs/Miss/Ms .....  
have agreed to take part in Well-TC study (Wellbeing in Thyroid Cancer study), qualitative study  
hosted by Newcastle upon Tyne NHS Foundation Trust, sponsored by Northumbria University and  
supported by the Butterfly Thyroid Cancer Trust.

The participant signed the consent form version.....dated..... and agreed to take part  
in.....(number) semi-structured interviews and/or keeping a reflective diary about their thyroid  
cancer lived experiences.

The study is looking into wellbeing and changes in wellbeing in time as well as factors affecting  
wellbeing during and after diagnosis. The study has the potential to contribute to the body of  
knowledge regarding wellbeing in thyroid cancer as well as helping to shape future research into  
interventions designed to help people in this situation.

If you would like more information about the study please see attached signed consent form and  
Participant Information Sheet version..... You can also contact the researcher Alicja Yilmaz for  
more information:

[alicja.yilmaz@northumbria.ac.uk](mailto:alicja.yilmaz@northumbria.ac.uk)

Tel: 07746312415

Project partially funded by Butterfly Thyroid Cancer Trust- a registered Thyroid Cancer Charity.

## Appendix 9

### Semi- Structured Interview Aide Memoire

**Project Title: Factors Affecting Wellbeing Among Thyroid Cancer Patients**

**Principal Investigator: Alicja Yilmaz**

**Example questions:**

**Before Treatment:**

- Tell me about your life before the diagnosis
- Tell me how did you found out about thyroid cancer?
- Please can you describe how you felt when you received the thyroid cancer diagnosis?
- Please can you describe how you felt when you heard about the treatment that would be involved?
- Can you tell me about your experience of treatment to date?
- What did you think at that time?
- How did your friends and family react to your diagnosis, treatment?
  
- What are your arrangements for child care/work etc?

**During/After treatment: Above plus:**

- How did you cope with your family commitments? (After treatment begins)
- How did you cope with your work commitments?
- What was/has been the most difficult part of the process?
- What did you take most encouragement from?
- What was the biggest challenge in the cancer journey?
- What support did you have, wellbeing interventions etc?
- How did you cope with diagnosis/Treatment?
  - a. Surgery
  - b. RAI

### FOLLOW UP INTERVIEW GUIDE.

The questions for the follow up will be guided by the answers provided by the participants in the first interview.

### HINTS

**Experience questions:**

- Tell me more about that?
- What was it like for you?
- Can you describe an example?

**Feelings questions:**

- What did you think/feel at that time?
- How did it make you feel?

**Knowledge:**

- What treatment did you receive?
- Do you know how to access the services available to help you?

**Themes:**

- Feelings and thoughts
- Care received in hospital
- Coping with diagnosis
- Coping with symptoms
- Coping with surgery and RAI
- Family and friends
- Commitments (care, family, work)

**Appendix 10**

**MEDICAL INFORMATION FORM**

Project Title: Factors Affecting Wellbeing Among Thyroid Cancer Patients

Researcher: Alicja Yilmaz, Supervisor Dr Jamie Harding

<b>FULL NAME or study ID</b>	
<b>AGE</b>	
<b>MEDICAL HISTORY, DISABILITIES</b>	
<b>DIAGNOSIS/ DATE OF DIAGNOSIS</b>	
<b>TREATMENT PLAN</b>	
<b>NOTES</b>	

Signature of Health Care Professional (If filled by HCP.....Date.....

(NAME IN BLOCK LETTERS).....

Signature of researcher. (If filled by the researcher).....Date.....

(NAME IN BLOCK LETTERS).....

## Appendix 11

### Diary Guide

Project Title: Factors Affecting Wellbeing Among Thyroid Cancer Patients

Researcher: Alicja Yilmaz, Principal Supervisor: Dr Jamie Harding

#### How to fill your diary

Thank you for agreeing to participate in this part of the Well-TC study. Below, there are a few points that may help you in filling in the diary.

- Please fill the diary with your experiences and reflections regarding thyroid cancer and how it affects your life (living with the disease, treatment, relationships with friends, etc.)
- It is your diary, please fill free to write anything you wish to share. Please fill in both good and bad experiences and emotions. You are more than welcome to write unrelated things, just bear in mind the researcher will read the diary (unless you decide not to return it which is fine).
- Please don't worry about spelling and grammar but try to write clearly so the researcher will be able to read it.
- Please fill in the diary as often as you are able to. Don't worry if you miss days at a time; please just carry on if you have had a break.

Please feel free to complete the diary in non-paper form if you prefer (e.g. recording on your mobile), so long as the researcher can access the material

If you have any questions about this diary, please contact Alicja Yilmaz on [alicja.yilmaz@northumbria.ac.uk](mailto:alicja.yilmaz@northumbria.ac.uk).

**Appendix 12**

**SCREENING FORM**

Project Title: Factors Affecting Wellbeing Among Thyroid Cancer Patients

Researcher: Alicja Yilmaz, Supervisor Dr Jamie Harding

<b>NAME</b>	
<b>DIAGNOSIS and date of diagnosis</b>	
<b>TREATMENT PATHWAY</b>	
<b>AGE</b>	
<b>OCCUPATION/ Employment situation</b>	
<b>MARITAL STATUS</b>	
<b>CHILDREN</b>	
<b>PROSPECTIVE LONGITUDINAL/ RETROSPECTIVE LONGITUDINAL (for the researcher only)</b>	
<b>RECRUITED</b>	<b>YES/NO</b>

Signature of researcher..... Date.....

(NAME IN BLOCK LETTERS).....

## Appendix 13

### WELLBEING IN THYROID CANCER STUDY

#### HAVE YOU JUST FOUND OUT THAT YOU HAVE A THYROID CANCER? OR HAVE YOU HAD THYROID CANCER IN THE LAST 5 YEARS?

A PhD Researcher/Research Nurse Alicja Yilmaz is looking to recruit patients to a new Wellbeing study.

The study involves telephone **INTERVIEW** and/or completing a reflective **JOURNAL**.



If you are interested in taking part in this study, or would like to receive more information about it, please contact: Alicja Yilmaz on:

[alicja.yilmaz@northumbria.ac.uk](mailto:alicja.yilmaz@northumbria.ac.uk)

07746312415

Project partially funded by Butterfly Thyroid Cancer Trust- a registered charity.



## Appendix 14

### Support available for you.

#### Butterfly Thyroid Cancer Trust

- Contact: The Butterfly Thyroid Cancer Trust
- Tel: 01207 545469
- [www.butterfly.org.uk](http://www.butterfly.org.uk)

#### British Association for Counselling & Psychology

Can provide a list of trained counsellors

- 01455 883300
- [www.bacp.co.uk](http://www.bacp.co.uk)

#### Maggie's Centre

The Centre is part of the nationwide [Maggie's Cancer Centre network](#).

Get in touch at:

- Email: [newcastle@maggiescentres.org](mailto:newcastle@maggiescentres.org)
- Tel: 0191 2336600

Address: Maggie's Centre, Freeman Hospital, Freeman Road, Newcastle, NE7 7DN

#### Berwick and District Cancer Support Group

- Office 4, Berwick Voluntary Centre, 5 Tweed Street, Berwick upon Tweed, TD15 1NG
- Tel: 01289 303839 (24 hrs)
- Email: [info@berwickcancersupport.co.uk](mailto:info@berwickcancersupport.co.uk)
- Website – [www.berwickcancersupport.co.uk](http://www.berwickcancersupport.co.uk)

The groups provide:

- Free transport to and from hospital appointments.
- Practical help and advice

#### Central Palz

- C/o Seaton Hirst Primary Care Centre, Norham Road, Ashington, Northumberland, NE63 0NG
- Tel: 01670 842021 (Service Manager: Mon – Fri 9.00am - 5.00pm)
- Email: [liz.harmer@gp-a84028.nhs.uk](mailto:liz.harmer@gp-a84028.nhs.uk)
- Website: [www.northumberlandlife.org/centralpalz](http://www.northumberlandlife.org/centralpalz)

Accepts referrals from primary and secondary care, and provides (for patients and carers):

- Social interaction and outings
- Complementary therapies
- Physiotherapy/gym
- Counselling
- Internet access
- 

#### Cancer Connections

- 85/91 Boldon Lane, South Shields, Tyne & Wear, NE34 0AS
- Tel: 0191 4565081
- Email: [info@cancerconnections.org.uk](mailto:info@cancerconnections.org.uk)

- Website: [cancerconnections.org.uk](http://cancerconnections.org.uk)

The group provides:

- Drop in service for patients and/or carers
- Friendship
- Emotional/Practical help/support (including home visits)
- Counselling
- Complementary Therapies
- Benefits/Financial advice
- Advice/Support in the event of bereavement

#### Northumberland Cancer Support Group

Offers support and friendship to people affected by cancer and their families.

- Meetings held weekly on Tuesdays, 7.30pm in the Education Centre, Hexham General Hospital, Corbridge Road, Hexham, NE46 1QJ (one meeting per month (fourth Tuesday) involves an invited speaker or specialist complementary therapist).
- Tel: 01434 622392 (Mary Miller) or 01434 230398 (Jim & Dee Townsend).
- Email: [info@northumberlandcancersupportgroup.co.uk](mailto:info@northumberlandcancersupportgroup.co.uk)
- Website: [www.northumberlandcancersupportgroup.co.uk](http://www.northumberlandcancersupportgroup.co.uk)

#### Macmillan Cancer Information and Support Centre

Northern Centre for Cancer Care  
Freeman Hospital  
Newcastle upon Tyne  
NE7 7DN

- Tel: 0191 213 8611 (voicemail)
- Opening hours: Mon – Fri 9.00am – 4.30pm
- [www.newcastle-hospitals.org.uk](http://www.newcastle-hospitals.org.uk)

#### Gateshead Cancer Information Service

Hancock Building  
Queen Elizabeth Hospital  
Sheriff Hill  
Gateshead  
NE9 6SX

- Tel: 0191 445 2979
- Opening hours: Mon – Fri, 10.00am – 4.00pm
- <http://www.gatesheadhealth.nhs.uk>

#### Macmillan Information & Support Service

Sir GB Hunter Memorial Hospital  
The Green  
Wallsend  
NE28 7PB

- Tel – 0191 220 5908

#### Cancer Information Centre – Chester-le-Street

Chester-le-Street Hospital  
Front Street  
Chester-le-Street  
County Durham

DH3 3AT

- Tel: 0191 387 6303
- Opening times: Tuesdays 10.00am – 1.00pm

(Please call before making a special journey to ensure the centre is open)

#### Cancer Information Centre – Durham

University Hospital North Durham  
East Wing Corridor  
UHND  
Durham  
DH1 5TW

- Tel: 0191 333 2815
- Opening times: (normally) 10.00am – 4.00pm weekdays

(Please call before making a special journey to ensure the centre is open)

#### Macmillan Information and Support Centre – Sunderland

City Hospitals Sunderland  
Kayll Road Entrance B Floor  
Sunderland  
SR4 7TP

- Tel: 0191 541 0122
- Opening times: 10.00am – 4.00am Monday - Thursday, 10.00am – 1.00am Friday
- Open once a month on Sundays.

#### Macmillan Cancer Information and Support Centre – Shotley Bridge

Shotley Bridge Hospital  
Woodlands Road  
Consett  
County Durham  
DH8 0NB

- Tel: 01207 594 660
- Opening times vary; please call to make an appointment.

#### Macmillan Cancer Information and Support Centre – Bishop Auckland

Outpatients Department  
Ground Floor  
Bishop Auckland Hospital  
Cockton Hill Road  
Bishop Auckland  
DL14 6AD

- Tel: 01388 455 230
- Opening times: 10.00am – 4.00pm, Mon – Fri

#### Macmillan Cancer information Centre – Newton Aycliffe

Pioneering Care Centre  
Cobblers Hall  
Newton Aycliffe  
DL5 4SF

- Tel: 01325 321 234

- Opening times: 9.30am – 12.30pm, Monday, Wednesday and Friday
- Freephone 0800 178 3277 (Monday – Friday 9.30am – 4.30pm)

#### Macmillan Cancer Information and Support Centre – Peterlee

20 Upper Chare  
 Castle Dene Shopping Centre  
 Peterlee  
 County Durham  
 SR8 1BW

- Tel: 0800 327 445
- Opening times: 9.30am – 4.30am, Monday – Friday

#### Macmillan Information and Support Centre – Darlington

Darlington Memorial Hospital  
 Hollyhurst Road  
 Darlington  
 County Durham  
 DL3 6HX

- Tel: 01342 743 008
- Opening times: Normally 10.00am – 4.00pm weekdays
- [www.cddft.nhs.uk](http://www.cddft.nhs.uk)
- Please call before making a special journey to ensure the centre is open

#### Macmillan Advice and Information

The George Hardwick Foundation - Hartlepool  
 University Hospital of Hartlepool  
 Hartlepool  
 TS24 9AH

- Tel: 01642 522 201
- Opening times: 9.00am – 5.00 Monday – Friday (by appointment only)

#### Macmillan Information and Support Centre – North Tees and Hartlepool

The George Hardwick Foundation  
 Main Foyer  
 University Hospital of North Tees  
 Stockton-on-Tees  
 TS19 8PE

- Tel: 01642 383 924
- Opening times: 9.00am – 7.00pm, Monday – Friday

#### Macmillan Cancer Information and Support Centre – Middlesbrough

James Cook University Hospital  
 Marton Road  
 Middlesbrough  
 Teesside  
 TS4 3BW

- Tel: 01642 835 674
- Opening times: 9.00am – 4.00pm, Mon – Fri

## Samaritans

24 hour listening service for anyone in distress or despair.

- 08457 909 090
- [www.samaritans.org.uk](http://www.samaritans.org.uk)

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