Exploring Endocrinologists' views and experiences of psychosocial and self-management support for patients with hypothyroidism

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Abstract

Background:

Hypothyroidism affects between 2% and 5% of the UK population. Reports suggest that up to 15% of patients report persistent symptoms despite treatment. Recommendations exist for psychosocial and self-management support for patients to address the demands of living with their condition and to develop the skills, knowledge, and experience to manage their health. In this study, Endocrinologists were asked about the provision of support for patients with hypothyroidism in secondary care. Their views, experiences, and perceptions of the barriers and facilitators to the implementation of psychosocial and self-management models of care were explored.

Methods

Eighteen Consultant Endocrinologists in the UK were recruited via a snowballing sampling technique and interviewed. Interviews were analysed using reflexive thematic analysis.

Findings

Four overarching themes were identified. In the first theme (‘Walk with them’) participants identified that patients with hypothyroidism have diverse needs for psychosocial and self-management support from the point of diagnosis, but that participants report varied will, skill and confidence to meet these needs. The second theme (‘Embedded is best’) encapsulates participants’ attempts to explore psychosocial issues and embed components of self-management support into their own practice. Difficulties in shifting the focus of the consultation towards self-management and subsequent challenges to professional identity as biomedical expert are reported. These were perceived to be confounded by debates about non-standard (T3) treatments for hypothyroidism and a lack of available support services for referral. The third theme (‘Incorporate and collaborate’) presents participants’ views that collaboration is required to address gaps in provision in primary and secondary care. Valuable partners include: Patients, Endocrine Nurses, Health Psychologists, Pharmacists, Exercise Physiologists, embedded Researchers, and experts in the charitable sector. The fourth theme (‘We can’t do this alone’) includes participant-identified barriers to progress and highlights a need for change. This includes increases in funding and research, and supportive environment which empowers clinicians to place patients at the centre of their care.

Conclusion

The findings from this research suggest that patients with hypothyroidism have unmet needs for psychosocial and self-management support from the point of diagnosis, and that Endocrinologists may to benefit from training, collaboration and support to incorporate non-medical models of care. Patients, professional collaborators, and experts in the charitable sector are valuable assets to Endocrinology and can contribute to psychosocial and self-management programmes for patients and clinician skills training, as well as acting as agents of change to address gaps in provision in primary and secondary care. A whole-systems approach is required to improve outcomes for patients with hypothyroidism and the clinicians who manage their care.

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Chapter 1: Aim, objectives and rationale

Exploring Endocrinologists' views and experiences of psychosocial and self-management support for patients with hypothyroidism

1.1. Aim and objectives

The aim of this research was to explore Endocrinologists' views and experiences of psychosocial and self-management support for patients with hypothyroidism.

The objectives of this research were:

- To examine Endocrinologists' views about the psychosocial and self-management support needs of patients living with hypothyroidism
- To examine Endocrinologists' experiences of providing psychosocial and self-management support within their own practice
- To examine whether Endocrinologists refer patients with hypothyroidism for additional psychosocial and self-management support
- To explore perceived barriers and facilitators to the implementation of psychosocial and self-management models of care

An overview of the role of Endocrinologists in the management of hypothyroidism is presented in section 2.3. (The Endocrinologists' Role) and definitions of psychosocial support and self-management used in this thesis are provided in sections 2.5 ('Systematic review: Do psychosocial interventions improve wellbeing and quality of life in adult patients with thyroid diseases?) and section 2.7. ('Defining psychosocial and self-management support')

1.2. Research Origins

This research originated when I was volunteering for the British Thyroid Foundation as part of my Professional Doctorate in Health Psychology.

My role was to provide evidence-based information and support to people with thyroid diseases via telephone and to develop and facilitate a monthly peer support group. During this time, patients described unmet psychosocial and self-management support needs, particularly for those with hypothyroidism. These ranged from wanting to know more about how to manage their condition, to dealing with mild problems (e.g. cold intolerance, skin complaints, memory problems), to more extreme issues (e.g. debilitating fatigue and suicidal thoughts and feelings).

This experience prompted me to carry out my doctoral systematic review into the effectiveness of psychosocial interventions for people with thyroid disorders during which, I found that very few interventions exist in the published literature for patients with thyroid diseases.

In fulfilment of my doctoral consultancy requirements, I subsequently collaborated with Endocrinologists in an NHS thyroid clinic for patients with persistent symptoms and complex needs to investigate their experiences of supporting this patient group in secondary care. Initially, I was interested in whether Endocrinologists and Health psychologists could collaborate to identify approaches and interventions to address the psychosocial and self-management concerns of this patient group. However, as I became immersed in this research area through consultancy and wider engagement with the participant group, I fostered awareness and sensitivity towards the professional and practice issues facing clinicians working this area. As my knowledge and expertise widened, and the position of trust between myself as a researcher and the participant group developed, I began to explore the management of hypothyroidism from the perspectives of participants, and the experiences and worldviews of the professionals became the central focus of the research. This progression led to an organic and changing research methodology, influenced by the evolving nature of the research question.

During this project, clinicians identified a need for support to meet patients' psychosocial and self-management needs but highlighted gaps in their own practice and in wider service provision. To examine whether this is a wider need in Endocrinology departments, this qualitative exploration was developed to explore the views and experiences of 18 Endocrinologists from a range of secondary care settings across the UK.

Throughout the course of this research, my approach and role developed from an initial patient facing role to adopting a focus upon professional issues in the management of hypothyroidism.

Chapter 2: Introduction and background literature

Exploring Endocrinologists' views and experiences of psychosocial and self-management support for patients with hypothyroidism

This chapter introduces hypothyroidism as the focus of this research and Endocrinologists as study participants. It outlines the history of medical treatments for hypothyroidism and findings from a systematic review which highlights a need for additional psychosocial and self-management support. The benefits of incorporating psychosocial and self-management models of care into the management of long-term conditions are described, as well as the impact of health professionals' attitudes and beliefs about these models upon health outcomes. This chapter builds upon the current literature about the beliefs and behavioural components contributing to the management of hypothyroidism in primary care (Dew et al, 2018). It describes the wide-ranging biopsychosocial support needs of patients with hypothyroidism identified in the literature and provides the rationale for exploring Endocrinologists' views and experiences of psychosocial and self-management models of support in secondary care.

2.1 Hypothyroidism

Hypothyroidism is a chronic condition affecting between 2% and 5% of the population in the UK (Saravanan et al, 2002). Hypothyroidism is a growing problem, which is 10 times more likely in females than males (British Thyroid Foundation, 2015; Taylor et al, 2018). Levothyroxine Sodium (LT4), a manufactured form of the thyroid hormone thyroxine (*T4*) is the recommended treatment for hypothyroidism and is currently the third most prevalently prescribed drug in the UK (NHS Digital, 2017).

There are two main causes of hypothyroidism; autoimmunity (Hashimoto's disease) and due to a side effect of treatment for an overactive thyroid or for thyroid cancer. Together these two types account for over 90% of all cases of hypothyroidism in the UK (Okosieme, et al 2016). Rarer causes stem from primary hypothyroidism (direct impairment of the thyroid gland function) which may result from abnormal fetal development, iodine deficiency, or inflammatory responses to drugs or pregnancy. Patients may present with mild biochemical changes (subclinical hypothyroidism) or with profound biochemical change (e.g. myxedema coma). Current guidelines for thyroid hormone replacement therapy recommend a one size-fits-all testing and treatment approach with synthetic LT4 monotherapy (Okosieme et al, 2016; NICE, 2019), an inactive thyroid pre-hormone which is known to be converted into the active thyroid hormone triiodothyronine (T3) in the body.

2.2. Complexity and persistent symptoms

Evidence exists that between 10-15% of patients with hypothyroidism (Wersinga, 2014; Chaker et al, 2017) report persistent symptoms, despite treatment with Levothyroxine (LT4), fuelling debates about the efficacy of the current gold standard treatment for hypothyroidism (described in section 2.4. 'The history of treatment for hypothyroidism'). Numerous and often debilitating residual physical, psychological, and cognitive symptoms, and ongoing social impacts have been reported in the literature.

Persistent physical symptoms reported in the literature include; widespread malaise (Mandincova, 2012); exercise intolerance (e.g. Lankhaar et al 2014); muscular complaints and myalgia (Reuters et al, 2012); increased lethargy and fatigue (Van de ven et al, 2012), weight gain (Sanyal & Raychaudhuri, 2016); lowered fertility and increased risk of miscarriage or preterm birth (Earl et al, 2013) and a higher incidence of co-existing autoimmune, inflammatory, and rheumatic diseases in patients with autoimmune thyroid diseases (Punzi & Betterle, 2004; Spirkova et al,2015; Fallahi et al, 2016).

Self-reported psychological symptoms include: poor general mental health (e.g. Saravanan et al, 2002), anxiety and depression (e.g. Alsaffar et al, 2016); psychiatric symptoms (Degner et al 2015); mood disturbance (Nexø et al, 2015a), and sexual dysfunction (Haider et al, 2016). Studies have found that patients treated with levothyroxine (LT4) therapy display significant impairment in psychological wellbeing compared to controls of a similar age and sex (Saravanan et al, 2006; Saravanan et al, 2002; Paniker et al, 2009; Wekking et al, 2005; In Taylor et al 2019).

The hidden, ambiguous and persistent nature of thyroid disease has been reported to result in lasting impacts upon patients' long-term health related quality of life (e.g. Watt et al, 2006). For example, patients with hypothyroidism (and hyperthyroidism prior to treatment to render them hypothyroid) have reported poor relationships with others resulting from their symptoms being subjective and invisible to others (Nexø et al, 2015a). Other reports of quality of life impacts include: impaired body image resulting from visible scars following thyroidectomy (e.g. Sethukumar et al, 2018) cosmetic eye changes associated with thyroid autoimmune overactivity (Nexø et al, 2015a; Jenkinson & Wickwar; 2016), and increases in body weight accompanying hypothyroidism (e.g. Kelderman-Bolk et al, 2015); as well as findings of poor voice recovery after thyroid surgery (Pernambuco et al; 2015); and reports of work disability, lowered productivity and loss of income (Thilvum et al, 2014, Brandt et al, 2015).

Patient reports of persistent physical, psychological symptoms and their impacts have contributed to debates regarding the adequacy of the current treatments available (described in section 2.4. 'The history of treatment for hypothyroidism'; e.g. Panicker et al, 2009b; Saravanan et al, 2006; McAninch &Bianco, 2016) and to recommendations within this thesis to address hypothyroid patients' wellbeing through the implementation of psychosocial support and self-management models of care, derived from studies carried out with patients reviewed in section 2.8. ('Reviewing the psychosocial and self-management support needs of patients with hypothyroidism').

Despite recommendations made in the literature to address persistent biopsychosocial symptoms of hypothyroidism through psychosocial and self-management support; few interventions for this patient group are known to exist. Difficulties in defining and addressing issues relating to quality of life in this patient group also persist due to the heterogenous definitions and measures of psychosocial concern and quality of life throughout the existing literature (see section 2.5. 'Systematic review: Do psychosocial interventions improve wellbeing and quality of life in adult patients with thyroid diseases?). The many ways that quality of life can be measured has made its incorporation into research and systematic review difficult (e.g. Theofilou, 2013) and a key criticism of the existing literature described above includes the use a range of measures which are not validated for use with this patient group including the General Health Questionnaire (e.g. Saravanan et al, 2002) and the Hospital Anxiety and Depression Scale (e.g. Alsaffar et al, 2016).

2.3. The Endocrinologists' Role

Endocrinologists assess complex cases of hypothyroidism referred from primary care and see patients for whom symptoms of hypothyroidism, or blood test results outside of the normal reference range, do not resolve with standard LT4 treatment.

The Endocrinologist role includes identifying the source of unresolved symptoms and treating accordingly when the cause is attributed to an endocrine issue; referring patients to other specialists to determine other causes or discharging patients back to primary care. They assess clinical need in patients requesting additional trials of Liothyronine (LT3) treatment (the active thyroid hormone triiodothyronine') which must be prescribed in secondary care (see section 2.4. 'This history of treatment for hypothyroidism'). More recently, due to new government guidelines, Endocrinologists are increasingly tasked with reviewing patients who have been using LT3 to improve their symptoms, with a view to re-assessment (i.e. to reduce numbers due to cost implications). Evidence suggests that this is increasingly problematic for their role in terms of professional autonomy and workload (e.g. BBC News, 2017), and in addressing patient relations and reported quality of life (see section 2.4. The history of treatment for hypothyroidism).

Endocrinologists are ideally placed to learn from regarding the reasons for the reports of persistent symptoms reported in the literature, and about the provision of psychosocial and self-management support known to those working with patients in secondary care. Insights from Endocrinologists may help us to learn more about the facilitators and barriers that help or hinder hypothyroid patients when managing their symptoms and also about what can empower them to develop the knowledge, skills and confidence to manage their health (Hibbard et al 2005) as identified as a need in the research literature (see section 2.8. 'Reviewing the psychosocial and self-management support needs of patients with hypothyroidism').

To date, no published literature exists that describes the ways that Endocrinologists view or manage the psychosocial or self-management needs of hypothyroid patients, including a lack of instruction within clinical guidelines (e.g. NICE, 2019); and little is known about the existing channels of referral or skills development programmes to support Endocrinologists to help this patient group. Endocrinologists work closely with other specialities when managing patients with specialist endocrine conditions (e.g. pituitary, parathyroid, diabetes, antenatal and adrenal clinics) but clinical guidance does not recommend a multi-disciplinary approach for the management of hypothyroidism (e.g. NICE, 2019). Whilst this suggests that Endocrinologists occupy an autonomous role in the management of hypothyroidism, emerging evidence suggests that Endocrinologists currently face difficult challenges in their role, balancing demands for autonomous clinical decision making with working within regional prescribing guidelines, leaving them in an unusual position between their patients and the healthcare system. These issues are explored further in the following section (2.4. The history of treatment for hypothyroidism).

2.4. The history of treatment for hypothyroidism

This section outlines the history of the treatment for hypothyroidism, during which interventions to reduce and standardise testing and treatment options for hypothyroidism were introduced, resulting in complaints about loss of quality of life from patients and difficulties for clinicians treating patients who present with persistent symptoms.

Since the 1970's, the field of Endocrinology has undergone a series of changes and transformations aimed at incorporating new evidence-based practices (EBPs; Bauer et al, 2015) into routine clinical usage (see McAninch &Bianco, 2016 for a review). These aimed to standardise and improve the safety of treatment of hypothyroidism through establishing (synthetic) Levothyroxine LT4 thyroid hormone monotherapy as standard clinical practice. During this period, the use of traditional pharmacologic treatments was phased out due to concerns about dosing and stability (Toft, 1999, Taylor et al, 2019). These included unlicensed natural desiccated thyroid preparations (NDT) derived from animal sources, and combination therapy with Levothyroxine Sodium (LT4) with Liothyronine (a manufactured form of the thyroid hormone triiodothyronine/*LT3*). Teaching regarding the use of natural thyroid hormone preparations (NDT) in medical education ended in the mid 1970's (Thyroid Patient Advocacy Forum).

During this period, a subsection of patients continued to report preference for discouraged treatments (Dayan & Paniker 2018) and many began to complain about loss of quality of life (Bunevicius et al, 1999). In response, 14 clinical trials were carried out to examine the effectiveness of LT4 monotherapy versus LT4/LT3 combination therapy. These trials, along with four systematic reviews and meta analyses found no clear benefit of LT4/LT3 combination therapy over levothyroxine LT4 monotherapy (Escobar-Morreale et al 2005; Joffe et al 2000; Grozinsky-Glasberg et al, 2006; Ma et al 2009; In Taylor et al, 2019).

Subsequent interventions were introduced to reduce 'unnecessary and costly' investigative and diagnostic blood tests and to establish TSH testing (a single laboratory parameter) as standard practice. These interventions targeted the behaviours of new doctors and trainees in medical education (e.g. Daucourt et al, 2003), alongside targeting practicing clinicians. For example, a systematic review (Zhelev et al, 2016) identified 27 studies of interventions to reduce the volume of thyroid tests ordered by GP practices across the UK. Evidence showed that this established a broad consensus in clinical practice patterns in the management of primary hypothyroidism (Burch et al, 2014). These patterns were consistent with wider drives in medicine to increase clinicians' adherence to guidelines to improve patient outcomes (Pronovost, 2013) and to improve implementation of 'value-based healthcare' amidst shrinking resources and increasing demand (Gray, 2017).

Despite the development of clinical guidelines and efforts to change clinician behaviour, it is believed that around 10-15% of patients with hypothyroidism complain of persistent symptoms (Chaker et al, 2017; Wiersinga, 2014, Peterson et al, 2018), and thyroid hormone replacement in primary care remain suboptimal (Dew et al, 2018). Subsequently, the majority of published national guidelines (e.g. European Thyroid Association, British Thyroid Association and American Thyroid Association) recognise that a subgroup of patients with hypothyroidism exist with persistent symptoms who may benefit from personalised therapeutic trials of T3, following discussion with the patient of the uncertainty, risks and benefits (Okosieme et al, 2017; Taylor et al, 2019).

Controversy in this area occurred in 2017 when Liothyronine (LT3), the active T3 thyroid replacement hormone was included in the NHS England (2019) consultation document 'Items which should not be routinely prescribed in primary care' leading to many CCGs in the UK issuing a blanket ban on the prescribing of medicines perceived to be of 'low value', including LT3. This resulted in the forceable withdrawal of prescribed LT3 from many patients and restrictions on prescribing practice upon clinicians. This was introduced by many CCGs despite significant patient evidence being submitted in response to the consultation from patients, patient advocacy groups (e.g. National Voices, 2018) and medical groups (e.g. Royal Pharmaceutical Society, 2018) advising against this change. The situation provoked campaigns from patient groups; a subsequent debate in the House of Lords in June 2018 and a meeting of key thyroid groups in the House of Commons in July 2018 (Hansard Online 21 May 2018) supporting the rights of treated patients with persistent symptoms to retain the use of LT3 therapy (British Thyroid Foundation et al, evidence dossier; 2018) advocating for improvements in the treatment of hypothyroidism.

The NHS England consultation process subsequently resulted in the reiteration of the need for exemptions from blanket bans of LT3 (liothyronine) for patients treated with LT4 (Levothyroxine) with persistent symptoms (Regional Medicines Optimisation Committee, 2018), but concluded that trials of LT4/LT3 should not be instigated in primary care, with responsibility and workload attributed to the clinical judgement of individual Endocrinologists in secondary care (BBC News, 2017). More recently however, the new guidelines (NICE 2019) advised against initiation of personalised medical trials due to gaps in the evidence whilst recognising that there may be a subgroup of patients for whom LT4 therapy may be ineffective.

Recently, data derived from a study of 797 Clinical Endocrinologists in Italy (Negro et al, 2019) showed that nearly 99% of Italian Endocrinologists agree with LT4 monotherapy as the standard treatment of choice, but that combination LT4 + LT3 is considered by 43% for LT4-replaced patients with normal TSH reporting persistent symptoms. However in this survey, high percentages of respondents reported using alternative LT4 formulations (e.g. liquid solution or soft-gel capsules) for patients with specific conditions (interfering drugs, actual or suspected malabsorption, inability to take LT4 in the fasting state, unexplained poor biochemical control of hypothyroidism) and 43% reported considering these for patients for LT4- treated patients with persistent symptoms. Whilst this study suggests that there may be alternative biomedical tools for addressing the problem of persistent symptoms of hypothyroidism; these are not currently available through the NHS.

In practice, individual CCGs in England currently continue to make local decisions regarding the availability and status of LT3 thyroid hormone replacement therapy as the key alternative to LT4 monotherapy, leaving patients subject to a postcode lottery of provision (Taylor et al, 2019). Many patients seek prescriptions privately from Endocrinologists or import LT3 from international sources and self-medicate without engagement from NHS healthcare providers, leading to concerns about risk and patient safety (Taylor et al, 2019).

Between 2014 and 2019, published studies have criticised the original research on which the clinical guidelines are based (e.g. Wersinga, 2014). Criticisms include heterogeneity of studies and inaccurate administration of LT4 and LT3 during historical trials when scientific knowledge of dosing was limited. In studies where patients preferred LT4 monotherapy to LT3 or LT4/LT3 combination therapy, it was found that high doses of LT3 were administered leading patients towards overreplacement and symptoms of thyrotoxicosis.

Whilst criticisms of the research have emerged, and a clearer picture of the scientific ‘knowns’ and ‘unknowns’ in this area are being mapped (Taylor et al 2019), clinical evidence for personalised medical treatment of LT4/LT3 combination therapy and natural thyroid preparations remains weak (Hennessey & Espillat, 2018) and clinical guidelines continue to discourage therapeutic trials (NICE, 2019).

This situation perpetuates unresolved debates about the necessity, superiority, cost effectiveness and potential side effects of the treatment for hypothyroidism throughout the literature (e.g. Toft, 2002; Toft, 2017; Kalra & Khandelwal, 2011; Hennessey & Espaillat, 2018; Tariq et al, 2018; Dayan & Paniker, 2018, Taylor et al, 2019.2) whilst patient reports of persistent symptoms and dissatisfaction with treatment persist (see section 2.2. ‘Complexity and persistent symptoms’).

Criticisms of clinical guidelines call for open minded approaches to prescribing (McAninch &Bianco; 2016; Toft 2017; Tariq et al 2018, Hoermann et al 2013, Hoermann et al 2018), and shifts away from the recent standardisation of clinician behaviour (Pronovost, 2013; Jonklass et al, 2019). Improvements to the research evidence in this area and new paradigms and ways of working are now required to address the recent surge in patient complaints about quality of life (Hoermann et al, 2017; Toft 2017; Midgley et al, 2019).

Current controversies and debates regarding the cause and prevalence of persistent symptoms, and regarding the need for a personalised versus one-size-fits-all approach to treatment has reportedly left some Endocrinologists and General Practitioners feeling stuck between a rock and a hard place with the implementation of guidance (Wilkinson, 2018) and concerned about mounting pressure upon their role (BBC News, 2017).

Clinicians have described a need for greater flexibility from CCGs who encourage them not to issue prescriptions of LT3, despite patient demand and GP contractual obligations (Wilkinson, 2018). A significant Increase in the cost of LT3 prescriptions has been attributed as the key driving factor in the continued denial of patient choice (Toft, 2017). Dependence upon reductionist diagnostic tests and rigid clinical guidelines (Toft, 2017) which negate thyroid patients' reports of unresolved symptoms (National Voices 2017), have been described as diminishing the willingness of GPs and Endocrinologists to explore and address the needs of those patients who present outside of the 'norm', particularly those who may require higher levels of LT4 or LT4/LT3 combination therapy or alternative LT4 formulations to alleviate their symptoms (Toft, 2017). This is reflected in the findings from a study which explored the treatment of hypothyroidism in primary care (Dew et al, 2018; see section 2.6. 'Examining clinicians' attitudes, beliefs and intentions towards self-management and psychosocial care'). This study found that primary care clinicians attributed professional responsibility to established clinical guidelines which did not always result in optimum hormone replacement. Endocrinologists who are willing to prescribe therapeutic trials of combination therapy or increased doses of LT4 have increasingly found their recommendations rejected by GPs or CCGs (Toft, 2017).

Some clinicians also question whether persistent symptoms reported by up to 15% of patients with hypothyroidism and growing reports of dissatisfaction with treatment may be attributable to non-thyroidal causes. Particularly, the wider prevalence of medically unexplained symptoms (MUS) in the general population, which account for 80% of all GP consultations (NHS Education Scotland, 2014), has been raised by some Endocrinologists as a possible explanation (Weetman, 2006). Others suggest that physical and psychological comorbidities contribute to the over-detection of subtle changes in thyroid biochemistry in people presenting with psychological and emotional complaints (Bekkering et al, 2019a).

NHS England (2018) have stated that two thirds of people with a chronic physical health condition also have a co-morbid mental health problem, mostly anxiety and depression; and up to 70% of people with persistent or 'medically unexplained symptoms' also have depression and/or anxiety disorders. Hi comorbidity of chronic conditions (e.g. Saravanan et al, 2002) and lower levels of psychological well-being have been found in patients treated for hypothyroidism (see section 2.2. 'Complexity and persistent symptoms'). However, controversies around the treatment of hypothyroidism, make it difficult to determine whether the phenomena of persistent symptoms in hypothyroidism results from a failure of standard treatment to resolve symptoms in some patients, or whether the large numbers of patients affected by hypothyroidism in the UK (between 2%-5% of the overall population; Saravanan et al, 2002) inevitably captures patients with unexplained medical symptoms or unresolved symptoms of physical and health comorbidities.

The significant evidence submitted by patients to the House of Lords shows that patients believe inadequacies in treatment to be the cause of persistent symptoms (BTF evidence dossier, 2018), and this is debated extensively in the existing literature with no definitive conclusion (e.g. Weetman, 2006; Saravanan et al, 2002; Naxo et al, 2015; McAninch &Bianco, 2016; Taylor et al, 2019).

Regardless of the cause of patient reported distress, a joint statement by national clinical leaders (Royal Society of Psychiatrists, 2015) stated that people who are troubled by persistent medical symptoms or symptoms inadequately explained by their medical condition are poorly served by existing services and state that there is an urgent need to provide them with more integrated physical and psychological healthcare to improve their quality of life and reduce costs to the National Health Service (NHS) and the wider system.

For health conditions with observed psychological impacts such as hypothyroidism, the World Health Organisation (2016) recommend basic training in providing 'embedded psychosocial support' for all healthcare providers, including training to assess who may need more than basic embedded support and what mental health and supportive and services are available to refer to. Such services may include psychology or counselling, peer support groups or more commonly, online support. The NHS England 'Implementing the Five Year Forward View for Mental Health' (2016) and 'NHS Long Term Plan' (Alderwick & Dixon, 2019) have pledged to expand access and referral to NICE-approved IAPT psychosocial support services (counselling, CBT and psychoeducation) for adults with common mental health problems with a focus on long term conditions over the next five years.

To conclude, recommendations exist in the literature to widen reductionist biological approaches to the management of hypothyroidism (despite clinical guidelines and behavioral interventions aiming to reduce personalised medical prescribing) and to incorporate new paradigms and ways of working to address reports of persistent symptoms and impaired quality of life in a subgroup of up to 15% of hypothyroid patients (see section 2.2. 'complexity and Persistent Symptoms').

What is apparent from reviewing the history of clinical treatments for hypothyroidism, however, is that little progress seems to have been made in the development of non-biological approaches to support patients to manage or improve the symptoms of their condition.

2.5 Systematic review: Do psychosocial interventions improve wellbeing and quality of life in adult patients with thyroid diseases?

In response to the findings in the previous section, a systematic review of the wider literature was conducted (Griffiths, 2017), and submitted as part of the current doctoral programme, to examine the existence and efficacy of psychosocial support to address reports of persistent biopsychosocial symptoms by patients with hypothyroidism.

The initial search of the literature was expanded beyond studies of patients with hypothyroidism to include patients with all thyroid diseases. This was to develop as wide an understanding of the available supportive interventions as possible. Secondly, it also aimed to capture interventions for thyroid conditions for which the treatment may result in hypothyroidism (for example Graves autoimmune thyroid overactivity, or thyroid cancer).

All psychosocial interventions were considered relevant within the scope of this review, and 'self-management' was included as a search term. However, the broad definition of 'psychosocial intervention' meant that it was difficult to ensure that finite definitions of psychosocial support were captured in the search strategy (described in Appendix L: 'Supporting information from systematic review'). This was compounded by the lack of evidence of guidance regarding the psychosocial concerns of patients with hypothyroidism in the clinical guidelines (e.g. NICE, 2019) and due to an absence of the management of hypothyroidism in the psychology literature.

The British Psychological Society (Guss et al, 2014) define 'psychosocial interventions' as a broad term used to describe ways to support people to overcome challenges and maintain good mental health which may include: adjustment to diagnosis, provision of general and specialist information, support with mood, quality of life, maintaining independence, communicating with others, maintaining relationships and planning for the future. The techniques involved in providing psychosocial support are many and varied and are tailored towards specific issues. These may include; targeting psychological symptoms, attitudes toward disease, risk behaviour, or social isolation (Deter, 2012) and addressing the condition-specific needs of patient groups based on findings from targeted research. For example, in the early stages of dementia, the recommended psychosocial interventions include cognitive behaviour therapy, counselling and psychotherapy, arts therapies, occupational therapy, family therapy, peer support groups, telephone support, stress and anxiety management, occupational therapy, and trauma therapy (Guss et al, 2014) as well as psycho-educational therapy for caregivers (e.g. Elvish et al 2013).

To overcome the issues regarding lack of clarity regarding the psychosocial concerns and potential interventions for patients with thyroid diseases, the search strategy for this review was adapted from a similar novel systematic review (Walklet et al, 2016) examining whether psychosocial interventions improve quality of life and wellbeing in adults with neuromuscular disorders. After identification of this paper, the author was contacted for discussion and the search strategy was adapted. For the present review, the terms 'multidisciplinary', 'nutritional', 'exercise' and 'pacing' were also added to further capture potentially relevant interventions (see Appendix L 'Supporting information from systematic review') for an overview of the inclusion and exclusion criteria, search strategy and list of databases searched).

Despite recommendations in the literature for supportive interventions for patients living with hypothyroidism (see section 2.8. 'Reviewing the psychosocial and self-management support needs of patients with hypothyroidism'), the systematic review found that only 8 studies met the eligibility criteria for inclusion as a psychosocial intervention for people living with a range of thyroid conditions, although the study was limited to English language articles. Additional interventions promoting specific nutritional protocols and supplements were considered outside of the scope of this review and were therefore excluded.

Included studies explored condition-specific education including leaflets (Crilly & Esmail, 2005; Lincoln et al, 2000); group information sessions (Alsaffar et al, 2016), mind-body interventions alongside traditional pharmacological therapy including Neuro-linguistic technique (Bablis & Pollard, 2009) and Neuro-emotional technique (Brown et al, 2015), graded exercise (Cotovic et al, 2012; Garces-Ateaga et al, 2013) and yoga (Singh, 2011). Most studies were of weak to moderate quality, whilst two higher quality studies found no significant effects of information (a leaflet; Crilly & Esmail, 2006) and a mind-body technique (neuro-linguistic technique; Bablis & Pollard, 2009).

It was found that, so far, interventions developed in the UK for patients with thyroid disorders have been informational/educational and have focused on brief, paper-based interventions (i.e. 'a leaflet to address thyroxine adherence'; Crilly & Esmail, 2005; or 'a leaflet versus single education session about thyrotoxicosis'; Lincoln et al, 2000). These have demonstrated no treatment effect; potentially resulting from reducing participants to passive recipients of care and possibly due to their failure to explore the illness beliefs, and adherence-related thoughts and feelings, knowledge or existing self-management skills of the target patient group.

The systematic review therefore concluded that more research is required is required to improve the quality of interventions for this patient group and to increase access to evidence-based support which moves beyond the treatment of patients as passive participants in their care. This contrasts with many other long-term conditions where self-management support promotes the role of patients as partners in the care process, for example; arthritis (Lorig, 1982; Lorig & Holman 2003; McBain et al, 2018), chronic pain (Tregar, 2014), CFS/ME (Castell et al, 2011; Núñez et al, 2011), rheumatology (Dures et al 2016a), and cancer (Polley et al, 2016).

One key omission from this review was that studies focusing on supporting or changing the behaviour of health professionals (including trainees) or other participant groups (e.g. caregivers and significant others) to address the needs of patients with thyroid diseases were considered out of the scope of inclusion. Incidentally, two studies that aimed to change the behaviour of medical professionals were found in the literature. One aimed to improve consultants' knowledge of a rare type of thyroid cancer by trialling an online sharing platform (Moss, 2010). The other aimed to reduce the amount of blood tests used for the detection of thyroid disease (which were described as costly and unnecessary), in line with reviewed US guidelines (Daucourt et al, 2003). This was directly in contrast with patient-centred research and calls from some clinicians to widen the scope of reductionist testing and treatment approaches (Toft, 2017; BTF evidence dossier, 2018) and calls to increase access to testing to translate patients' internal experiences into tangible explanations and diagnoses (e.g. Nexø et al, 2015a). No other studies in this area were identified during the course of the systematic review.

The present study was therefore developed to address this balance and move the focus of investigation towards Endocrinologists' views about the needs of patients with hypothyroidism reported in the literature and about the apparent gap in intervention provision to improve the physical, psychological and social health outcomes of this patient group.

2.6. Examining clinicians' attitudes, beliefs and intentions towards self-management and psychosocial care

For over 30 years, health psychologists have examined the role of patients' and doctors' knowledge and beliefs about their preference of treatment options, and the impact of these upon health outcomes. For example, in Endocrinology, beliefs about self-care have been highlighted as an important influence upon metabolic control in patients with diabetes since the 1990s (Bradley, 1990).

Health professionals' beliefs about psychosocial and self-management support have been found to directly influence health outcomes in patients with persistent symptoms and emotional distress. For example, in a study of 4,020 patients with cancer it was found that only 29% of patients who were identified by their doctor as 'psychologically burdened' were referred to psycho-oncology services for supportive care (Ernst et al, 2018). Similarly, whilst psychological distress attributed to persistent fatigue and pain is reported as commonplace amongst rheumatology patients, less than a quarter of patients reported being asked about social and emotional issues despite looking to rheumatology teams for validation and support (Dures et al, 2017).

A survey of 886 patients and 117 health care professionals in the UK found that only 15% of patients with inflammatory arthritis had attended a structured self-management support programme. In this survey, health care professionals reported beliefs that they were embedding elements of self-management support into consultations, but their patients did not agree, indicating significant disparities between doctor and patient beliefs about the delivery of elements of self-management support in routine care (McBain et al, 2018).

Ernst et al, (2018), suggest that a combination of patient beliefs (that they should receive psychological support from their doctor rather than a psychologist) doctor beliefs (underestimation of the extent of patients' psychological burden) and the consultation structure (lack of time for patients to express their psychological concerns) may act as barriers to referral to psychosocial care.

Further research into attitudes and beliefs about self-management support for patients with long term conditions (Anderson & Ozakinci, 2019) using the Theory of Planned Behaviour (Ajzen, 1991; 2002) found that specific beliefs (social norms and perceived control) were more instrumental in shaping health professionals' intentions to implement self-management models of care than the personal attitudes of the individual clinicians towards self-management. Healthcare professionals were less likely to implement supported self-management if they did not believe that 'important others' (patients and senior figures) were on-board with the model of care. Wider beliefs about cultural and organisational barriers (perceptions about level of control to implement the model) were also identified, demonstrating contextual mediators between attitudes and behaviours. This study concluded that addressing the social and control beliefs of healthcare professionals may be key to improving intention to implement evidence-based models of care (Anderson & Ozakinci, 2019).

A separate study which explored these issues with rheumatology clinicians showed that clinicians cited perceived barriers to psychosocial and self-management models of care to include: a lack of time in clinic; difficulties changing the existing pattern and focus of interaction; and concerns about exploring social and emotional aspects of living with arthritis. Perceived facilitators included: training that balances theory with time to practice skills and receive feedback; access to clinical supervision to gain confidence and develop more advanced techniques; and the perception that patients gain a greater sense of control and are better able to take responsibility for their treatment, as a consequence of a more collaborative consultation (Dures et al, 2014a).

In response, research which has developed and tested training for rheumatology clinicians to use a range of self-management skills (i.e. basic cognitive-behavioural skills and techniques to facilitate a collaborative interaction) found that clinicians were able to learn and implement new approaches to varying extents, and reported the belief that cognitive behavioural and communication skills to facilitate self-management enhanced their practice (Dures et al, 2014b). Additional studies have found that when embedded self-management support does occur, it is a significant predictor of patients' knowledge, skills, and confidence to self-manage, as opposed to attendance at a structured programme (McBain et al, 2018).

Specifically relating to the focus of this thesis, one study has explored the beliefs and behavioural components contributing to the management of hypothyroidism in primary care. This study (Dew et al, 2018) used the Theory of Planned Behaviour to examine primary care professionals’ attitudes, beliefs and behaviours regarding suboptimal thyroid hormone replacement (estimated to be between 31%-68% from studies cited). This study reported dissonance between attitudes and beliefs versus behaviours of primary care clinicians (GPs, nurses and pharmacists), elicited during qualitative interviews.

Clinicians’ attitudes towards hypothyroidism were that it is an easy condition to manage; and that blood tests (rather than reliance on non-specific clinical symptoms) should confirm diagnosis, and guide management. However, despite clinician’s attitudes that hypothyroidism is easy to manage, uncertainty existed about the treatment of asymptomatic patients with borderline biochemical changes, and gaps in knowledge regarding medicine interactions were identified. Difficulties particularly arose for clinicians when patients found information online about treatments (combination LT4/LT3 therapy or natural desiccated thyroid extracts/NTD) which did not fit with current clinical guidelines. This was problematic because clinicians attributed professional control to local guidelines rather than to clinician autonomy or patient reported outcomes. Only one doctor reported treating one patient in response to an autonomous patient-doctor agreement. Clinicians reported positive attitudes towards to personalised approaches to care, so long as treatment remained within normal population reference ranges.

These findings are congruent with arguments found in the literature that dependence upon reductionist diagnostic tests and rigid clinical guidelines which negate hypothyroid patients’ reports of unresolved symptoms (National Voices 2017) diminish the willingness of GPs and Endocrinologists to explore and address the needs of those patients who present outside of the 'norm' (Toft, 2017; see section 2.4. 'The history of treatment for hypothyroidism').

The findings of Dew et al (2018) reflect other findings in the published literature of clinician's attitudes towards self-managing patients. Here varied views have been reported regarding the roles that patients should take in their own care. Broadly, clinicians report being more likely to support patients' treatment choices, and to endorse healthful changes in accordance with clinical advice. However, clinicians report finding psychosocial and self-management models to be more problematic when they consist of patients making independent judgements or independently seeking information that may contradict clinical advice (e.g. NHS England, 2015). No studies yet exist to explore these findings in regard to patients with thyroid conditions.

2.7. Defining psychosocial and self-management support

The current study explores Endocrinologists' views and experiences of psychosocial and self-management models of support and their potential utility (including perceived barriers and facilitators) for hypothyroid patients referred to secondary care. It also examines whether Endocrinologists currently incorporate elements of psychosocial and self-management care into their practice or refer their patients to support services currently unevaluated for their impact on the physical, psychological and social health outcomes of patients living with hypothyroidism.

In this research, psychosocial support is considered an applicable area of focus because psychosocial models of care are utilised when a situation or health condition impacts the inner world of a person (i.e. their thoughts, feelings, and emotions) as well as the external world and environment of the person and the relationships they have with this (UNICEF, 2008). The definition of psychosocial support used in the context of this thesis is provided in section 2.5 ('Systematic review: Do psychosocial interventions improve wellbeing and quality of life in adult patients with thyroid diseases?'). In section 2.8. ('Reviewing the psychosocial and self-management support needs of patients with hypothyroidism'), the need for psychosocial support for hypothyroid patients is presented.

Psychosocial models of care address the psychological and social difficulties and community-identified needs of individuals, their partners, families and caregivers (World Health Organisation). They help people to adapt, cope better with distress and suffering and become reconciled to everyday life (International Federation of Red Cross and Red Crescent Societies). Psychosocial interventions include psychological therapies (e.g. cognitive behavioural therapy), psychoeducation and peer support which can be delivered to individuals or groups (Ruddy et al, 2005). Systematic reviews of the literature indicate that psychosocial interventions can improve quality of life and well-being in adults with long-term conditions (Rehse & Pukrop, 2003; Steed et al, 2003; Osborn et al, 2006).

Self-management support has also been chosen as a focus of investigation due to the utility of the model of care to address the key challenges faced by patients when living with chronic illness. Definitions of self-management in the literature include; "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition" (Barlow et al, 2002); "low intensity intervention that aims to encourage awareness of and active patient participation in chronic condition management, including physical symptom and emotional management" (NHS Education for Scotland 2014) and the development of 'healthful behaviours' through behavioural interventions (Lorig & Holman; 2003). Self-management approaches have been recommended for health problems that last a year or longer, impact on a person's life, and may require ongoing care and support (e.g. NHS Education for Scotland) and may therefore be suitable for patients treated for hypothyroidism, with persistent symptoms. Self-management support helps patients to develop the skills, knowledge and confidence to manage their health (NHS England, 2015).

Research within the self-management paradigm (described in Lorig & Holman, 2003) has categorised three sets of challenges that patients face when adjusting to living with chronic illness: namely medical, emotional and role management challenges. Medical management refers to adjusting to taking medications and adhering to specific treatment regimen. Emotional management refers to work required to manage the emotions (e.g. fear and anger) experienced by someone with a chronic disease. Role management involves maintaining, changing, and creating new meaningful behaviours or life roles. However, traditional patient education and health promotion programs have mostly been found to address medical and behavioral issues.

Research into self-management has identified core self-management skills—problem solving, decision making, resource utilisation, the formation of a patient–provider partnership, action planning, and self-tailoring (Lorig & Holman, 2003) and similarly, education, managing emotions, skills acquisition, self-monitoring, understanding illness, problem solving, goal setting, and action planning (Mulligan et al, 2009) as key to improving self-efficacy and helping patients to keep 'wellness' in their foreground perspective (Lorig & Holman, 2003). Approaches to the provision of self-management support include patient education, cognitive-behavioural approaches, health coaching, and peer support (NHS Scotland, 2014; NHS England, 2019a) and programmes which incorporate efficiency-enhancing techniques including skills mastery, modeling, reinterpreting physiologic symptoms and social persuasion (Lorig & Holman, 2003).

Self-management care belongs to a community-focussed family of interventions known as 'asset-based health frameworks' which adopt a different starting place to traditional medical models of care (see NESTA, 2020 for an overview). Asset-based frameworks are approaches which begin with identifying a community's capacities and encouraging it to help itself (Noble-Jones et al, 2019). They focus on patient-perceived problems (Corbin & Strauss, 1988; Lorig & Holman, 2003); foster and tap into the resources and capabilities of patients to enhance their health and wellbeing and promote resilience and independence (Finnis et al, 2016; Self-Management UK, 2017; Social Care Institute for Excellence, 2018). Asset-based frameworks including self-management care promote personalised care planning (Coulter et al 2013) which highlights the importance of a collaborative patient-provider partnership, combining professional expertise and lay (individual and community) experiential knowledge at the centre the creation of health (Von Korff et al, 2002).

Evidence-based self-management programmes aim to activate or empower patients to increase their participation in chronic condition management, including physical symptom and emotional management and engagement in healthful behaviours (Lorig & Holman; 2003; NHS Education Scotland 2014). They have been associated with a reduction in health inequalities, delivery of improved outcomes, better quality care and lower costs (e.g. Hibbard & Gilbert 2014; Anderson & Ozaninci, 2019; Self-Management UK, 2017). Supported self-management (SSM) is one of six key components of the 'Personalised Care model' presented in the NHS Long Term Plan (Alderwick & Dixon, 2019) which recommends that health and care professionals tailor their approaches to working with people, based on the person's individual assets, needs and preferences, as well as taking account of any inequalities and accessibility barriers, and so working in a personalised way based on 'what matters' to the person (NHS England, 2019a).

2.8. Reviewing the psychosocial and self-management support needs of patients with hypothyroidism

During the literature searching described in this chapter, the need for psychosocial and self-management support was identified for patients to manage the psychosocial aspects of living with hypothyroidism. This was initially described in terms of persistent physical, psychological, and cognitive symptoms, and ongoing social impacts in section 2.2. ('Complexity and persistent symptoms'). However, no evidence base for the implementation of psychosocial or self-management support for people with hypothyroidism was found (see section 2.3. 'The Endocrinologists' role') and few interventions were found to exist (section 2.5. 'Systematic review:

Do psychosocial interventions improve wellbeing and quality of life in adult patients with thyroid diseases?'). This section, therefore, provides a novel synthesis of recommendations highlighted in the literature. It serves to fill the gap left by the absence of pre-existing systematic reviews of literature in this area, and by the absence of recommendations to address the psychosocial concerns of this patient group in the clinical guidelines (see section 2.3. 'The Endocrinologists' Role').

Lorig et al, (2003) highlight that self-management support focuses upon on patient-identified concerns and problems, and whilst many concerns are shared across different diseases, behaviours, and populations, there are always differences between groups and individuals. They recommend a detailed needs assessment for each new topic and group of patients. This section provides a needs assessment for patients with hypothyroidism. In addition, it is the first attempt in the literature to relate the needs of patients with hypothyroidism to the components of self-management support (Lorig & Holman, 2003, and Mulligan et al, 2009) used to address the challenges of living with chronic illness (see section 2.7. 'Defining Psychosocial and self-management support').

The following section lists the support needs of patients with hypothyroidism and draws upon the components of self-management (Lorig et al, 2003 and Mulligan et al, 2009), to suggest possible approaches to meet these needs. 'Psychosocial support' is contained within multiple components, for example in information and education, communication skills training and specifically within the emotional management component. The recommendations are grouped according to the needs found in the literature rather than to potential interventions. Therefore, some duplication exists where a specific component of self-management support may be applicable to address more than one identified need. The creation of this set of recommendations played a key role in shaping the interview topic guide used with participants as described in section 3.9. ('Data collection. The Interview topic guide').

The literature derived from patients with hypothyroidism recommends that health outcomes may be improved if interventions aimed to:

1. Increase patients' knowledge and understanding of their condition and the consequences of suboptimal treatment or over-replacement of thyroid hormones (Brown et al, 2005; Dew et al, 2017); and provide treatment information and education on issues relating to the impact of the disease and treatment on quality of life (Grogan et al, 2016; Banach et al, 2013). Relevant components of self-management support (Lorig et al, 2003 and Mulligan et al, 2009) may include provision of informational and educational interventions and training for patients to find and utilise a range of information and resources.

2. Provide psychological support (Perros et al, 2015), on-going listening and responsive approaches to treatment and access to counselling to address the impact of hypothyroidism (Kirby, 2010); address concerns associated with body image and changed appearance or disfigurement (Farid et al, 2005; Wickwar et al, 2015); this should include support for the psychological aspects of weight changes (Kelderman-Bolk et al, 2015; Chaput et al, 2008), and cognitive and informational support to realistically manage patients' expectations of treatment (e.g. surgical outcomes for thyroid eye disease associated with an overactive thyroid prior to treatment to become hypothyroid; Jenkinson & Wickwar, 2016). Relevant components of self-management support (Lorig et al, 2003 and Mulligan et al, 2009) may centre around managing emotions.

3. Support patients to cope with poor control over mental and physical states (Naxo et al, 2015); develop skills to recognise the ambiguous aspects and symptoms of the disease and understand illness symptoms (Banach et al, 2013); provide greater access to blood testing to understand and communicate and internal experiences (Naxo et al, 2014); provide continuity of care and accessible testing and prescriptions (Dew et al, 2018) referral to multidisciplinary teams to manage wide ranging symptoms (Estcourt et al, 2015); and a need for prospective trials using intervention strategies known to work in other conditions (Grogan et al, 2016). Relevant components of self-management support (Lorig et al, 2003 and Mulligan et al, 2009) may include acquiring new illness-related skills to self-monitor and self-manage effectively, and promoting understanding of hypothyroidism to support day to day decision making in response to changes in symptoms or test results.

4. Develop communication strategies between patients and significant others: including addressing attitudes and communication styles of "unsympathetic" or "dismissive" doctors (Kalra & Khandewal; 2011) or significant others (Grogan et al, 2016); reducing cognitive dissonance in healthcare providers towards the management of hypothyroidism (Dew et al 2018); support to manage the effects of increased reliance upon relationships with family and friends (Naxo et al 2014) and support to negotiate ongoing sickness with employers and co-workers to reduce disproportionate income and pension losses (Thvilum et al, 2010). Relevant components of self-management support (Lorig et al, 2003 and Mulligan et al, 2009) may include developing patient–provider partnerships and supporting patients to be actively involved in solving problems.

5. Support patients to make healthy behavioural changes to increase resilience and promote recovery, including yoga, graded physical activity which include goal setting and targeted

nutrition with support from qualified professionals (Singh, 2011; Cutovic et al, 2012; Garces-Arteaga et al, 2013). Relevant components of self-management support (Lorig et al, 2003 and Mulligan et al, 2009) may include action planning to implement short term behavioural changes and self-tailoring (i.e. skills to apply knowledge and self-management skills to oneself as appropriate).

Following the identification of persistent biological, psychological and social symptoms in some patients with hypothyroidism; and the identification of recommendations for the provision of psychosocial and self-management models of care, the aims and objectives for this research were developed.

The aim of this research was to explore Endocrinologists' views and experiences of psychosocial and self-management support for hypothyroid patients. Specifically, the objectives of this research were to; examine Endocrinologists' views about the psychosocial and self-management support needs of hypothyroid patients; examine Endocrinologists' experiences of providing psychosocial and self-management support within their own practice; examine whether Endocrinologists refer patients with hypothyroidism for additional psychosocial and self-management support (as of yet unreported in the literature); and to explore perceived barriers and facilitators to the implementation of psychosocial and self-management models of care.

Chapter 3: Methodology and Method

This chapter describes the methodological framework through which this research was developed and provides the rationale for the use of the qualitative approach of reflexive thematic analysis. In the first part of this chapter, the aim, objectives, and design of this research are described in relation to issues regarding the trustworthiness and quality of qualitative research. In the second part of this chapter, a description of the method used to carry out this research is provided.

Methodology

3.1. Rationale for qualitative approach: Development of researcher's epistemological and theoretical stance

This research adopted a critical realist ontology and qualitative techniques for data collection and analysis to explore the views and experiences of participant Endocrinologists. Initially, this study was based on a systematic review and was built upon pragmatist worldviews and methodological assumptions that led to the inclusion of quantitative data and analysis in the research design. Subsequently, through the development and testing phases of this thesis, the basic assumptions on which the research was built were brought into question, leading to a change towards a Big Q, qualitative design (Kidder & Fine, 1987). Big Q qualitative research involves working up from the data in an inductive way rather than working deductively within pre-existing theoretical frameworks (Braun & Clarke, 2016).

This research began with an assumption that the models of care featured in this research (i.e. psychosocial and self-management) would be understood, accepted and valued by Endocrinologists given the inclusion of supported self-management, particularly of long term conditions, in the NHS Long Term Plan (Alderwick & Dixon, 2019). It was formerly a cross sectional, mixed methods study with an explanatory sequential design (Wisdom & Creswell, 2013). To meet the research objectives, a survey was designed to question Endocrinologists about their attitudes and practices, followed by qualitative interviews with a smaller subset of Endocrinologists to provide additional contextual insights and experiential accounts.

The original survey required Endocrinologists to complete the 'Clinician PAM' (CS-PAM), a validated tool which asks questions about clinician attitudes towards the active role of patients in the care process (Hibbard et al, 2010) alongside bespoke condition-specific questions as developed in similar studies with a quantitative approach (e.g. McBain et al, 2018). The CS-PAM is known to be a valuable positivist tool for deriving a 'score' or a 'level' of strength of endorsement of patient self-management, and for identifying differences between clinician groups (Rademakers et al, 2015). It also has utility in assessing pre- and post- scores of beliefs regarding the importance of patient knowledge and involvement, for example before and following an intervention targeting clinicians (NHS England, 2015).

However, in the early stages of research development, The British Thyroid Foundation (a patient-led thyroid charity) and three Endocrinologists were included as Patient and Public Involvement (PPI) contributors' (Locock et al, 2017) in the design and testing process. This aimed to help to decide which questions were important to be researched as recommended in good practice guidelines (e.g. National Institute for Health Research, 2019). One Endocrinologist rejected the topic of self-management as unimportant for patients with hypothyroidism and withdrew from the process (discussed in Chapter 5.5. 'Strengths and limitations'). A second suggested a consultancy project within their department to adopt a collaborative multidisciplinary approach to 'shine a light' of the topic to be explored thus demonstrating the importance of the topic to them (discussed in section '1.2. Research Origins'). A third Endocrinologist highlighted difficulty understanding the terminology relating to 'self-management' and suggested that their colleagues were also likely to struggle with the semantics used from a predominantly health psychology paradigm, particularly in the context of hypothyroidism.

After receiving three different responses to the project and the feedback from the third contributor, it became apparent that terminology intrinsic to asset-based models of care such as 'psychosocial' and 'self-management' support (e.g. Coulter et al, 2013; NHS England, 2014) were not congruent with the semantics and philosophical scientific worldview of participants trained within a medical model of care (Lang, 1981). The medical focus upon 'clinical management' rather than 'self-management' priorities for patients with hypothyroidism highlights a mismatch between multi-disciplinary models of health (Davey-Smith et al, 2001).

Communication theory (Lasswell, 1948) proposes that information is transferred via an assumed process of shared meaning and a set of common rules and understandings. The assumption of one version of reality or knowledge (Braun & Clarke 2013), on which the original research design was developed was challenged during the development stage and was subsequently rejected as presumptive, prompting a shift away from a realist evaluation of truth towards a qualitative examination of knowledge and meaning making.

Additional PPI activity in the form of collaborative consultation was carried out to immerse the researcher in the context of participants (see section 3.9. 'Data collection' for an overview). As a result, additional issues and debates in the field of Endocrinology were identified as salient to participants that were not captured by the initial literature search (which focused primarily on the needs of patients). This prompted further literature searching to understand the history and debates regarding the treatment of hypothyroidism (described in Chapter 2, section 2.4.; The history of treatment for hypothyroidism'). As a result of this additional searching, it became apparent that no evidence base or recommendations in the clinical guidelines exist to support healthcare professionals to manage the psychosocial concerns of patients with hypothyroidism (see section 2.3. 'The Endocrinologists' Role'). This new knowledge led to the rejection of the use of pre-existing quantitative tools and of the inclusion of health psychology models in favour of a qualitative research epistemology and design to enable issues of interest and importance to this participant group be explored.

Existing research with a similar focus to the current thesis have utilised health psychology models to understand or predict patient and clinician behaviour and to further understand the factors influencing the management of hypothyroidism. For example, Dew et al (2017) examined patients' beliefs about the treatment of hypothyroidism in general practice. This study used the Health Belief Model (HBM; Rosenstock, 1974) to deductively drive the analysis their qualitative data. Using the HBM, Dew et al (2017) generated themes about the beliefs of patients with hypothyroidism, relating to their ability and readiness to influence the control of their disease. The HBM was developed to examine patient health perceptions and behaviours (e.g. to inform interventions) rather than clinician views and intentions towards their patients and therefore had no rationale for inclusion in the present study. In a second study, however, Dew et al, (2018) used the Theory of Planned Behaviour (TPB; Ajzen, 1991, 2002) to map themes from coded interview data to identify the beliefs of primary care health professionals that mediate between an attitude (i.e. that hypothyroidism is relatively easy to manage according to clinical guidelines), and the translation of that attitude into intended behaviour (e.g. lack of knowledge or time). However, a key limitation of the TPB (e.g. Taylor et al, 2006) is that it assumes that behavioural intentions are precursors to behaviours. In the current thesis however, the starting point was a lack of definition of intended behaviour (i.e. shared understanding of self-management in the context of hypothyroidism or existing clinical guidelines towards the management of the psychosocial concerns of patients with hypothyroidism) leading to the decision that an initial exploratory approach to the problem was required.

In another similar study within endocrinology, McBain et al (2016) used the Theoretical Domains Framework (TDF; Atkins et al, 2017) to deductively code qualitative interview data regarding the barriers and facilitators healthcare professionals experience when implementing type 2 diabetes management guidelines in people with severe mental illness. The TDF was developed from theories relating to behaviour change and implementation science (Michie et al, 2011), from which specific constructs were identified and grouped into domains. The development of the framework aimed to provide a theory-informed approach to identifying determinants of behaviour and was initially developed to identify influences on health professional behaviour relating to implementation of evidence-based recommendations (Atkins et al, 2017). Similarly, in the absence of evidence-based recommendations in this area, the decision was made to move away from deductive theory-led models in favour of an inductive, participant-led approach to capture the ways that Endocrinologists view, experience and attribute meaning about this patient group and the potential treatment approaches.

This study adopted a critical realist ontology, which proposes a pre-social reality that we can only ever partially know through the accounts of social players (Neufield, 1994) and a contextualist epistemology which proposes that 'knowledge' is socially and contextually influenced (Madill et al, 2000). This lens was chosen to encourage Endocrinologists to tell their own stories; and to communicate the issues that were important to them, using their own language, knowledge, semantics, beliefs, and priorities; as well as to simultaneously examine the issues of interest to the researcher. Participants' views and experiences and perceptions of the perceived barriers and facilitators to psychosocial and self-management support were explored, as well as the broader social contexts that shape them (e.g. Willig, 1999).

3.2. Quality issues in qualitative research

Qualitative research has been described as a diverse field encompassing a variety of epistemological and ontological standpoints, often representing different procedures and standards and embracing different methodologies and epistemologies (Yardley, 2000). Establishing the quality and trustworthiness of qualitative research requires the awareness and acknowledgement of error (Oakley, 2000; Meyrick, 2006), and a recognition that representations of 'truth and knowledge' are shaped by the purposes, subjective and cultural perspectives, and conversations and activities inherent within research activity (Yardley, 1997). Assuring quality and trustworthiness in qualitative research requires consideration of the validity and utility of research for a certain purpose, particular situation and special community of people, as opposed to emphasis upon objectivity, reliability, and generalisability inherent to quality frameworks of positivist methodology (Yardley, 2000).

This research was conducted with awareness of good practice recommendations for quality and trustworthiness, rigour, and value within qualitative research (Yardley 2000; Meyrick, 2006). These principles acknowledge and analyse recognise the influence of the researcher in the production of knowledge (e.g. their influence upon the research findings), and the influence of participants in the development of the topic and data (e.g. through PPI or the use of open-ended questions interview questions) (Yardley, 2015).

Good practice recommendations (Yardley 2000; Meyrick, 2006) begin in the earliest stages of the research process, beginning with engagement with pre-existing knowledge relevant to the enquiry (in the present study, in the form of literature searching, PPI to include participants and key authors in the field and consultancy); to formulating a research question; the selection of appropriate methods (which recognise researcher epistemological and theoretical stance) and sampling approaches; the choice of appropriate tools for data collection and analysis; and the interpretation of findings and presentation of results and conclusions, in which value judgements and considerations about the breadth of application and practical utility are made. Yardley (1997; 2015) outlines four broad principles for assessing quality in qualitative research which govern the present study: sensitivity to context; commitment and rigour; transparency and coherence, and impact and importance.

Sensitivity to context

This research draws upon extensive engagement with theory and previous literature. This includes a systematic review and additional literature searching following a collaborative consultancy project to fully immerse the researcher into the practice and socio-political context of participants. Additional PPI activity including involvement of two Endocrinologists and expert patients from the British Thyroid Foundation was conducted to involve them in shaping the methodological approach and tools for data collection, to ensure that their values and experiences were included. Engagement with authors who have analysed similar topics was also carried out to understand existing philosophical approaches, perspectives, models, and tools and to shape choices made about approaches used in this study. For example, contact was maintained with authors of key papers included in Chapter 2 ‘Introduction and background literature’ (e.g. Dures et al 2014; McBain et al, 2018; Dew et al 2018) to achieve ‘vertical generalisation’ (Johnson, 1997), a term used to describe the usefulness of the insights gained from the resent research to other contexts with similarities (Yardley, 2015).

Commitment and rigour

This research addresses rigour through attention to sample selection and recruitment, to gain unique insights into the views and experiences of the target group. Prolonged engagement with the topic was carried out through literature searching and PPI activities (described above) through which the development of the methodological approach was developed (see section 3.2. Rationale for qualitative approach: Development of researcher's epistemological and theoretical stance'). This in turn, shaped decisions made about the appropriate tools for sampling, data collection and analysis (see section 3 'Methodology and Method') to be selected and studied for use with competence.

Transparency and coherence

The coherence of a study relates to the extent to which it makes sense as a consistent whole, and the openness and transparency of the influences which have developed and shaped it (Yardley, 2015). This research openly describes features that may have influenced the data or interpretations (including the rationale for the study in Chapter 1; 'Aim, objectives and rationale) and researcher positionality as a reflexive analysis of how these features could have influenced the conclusions reached (see section 3.12. 'researcher positionality').

During the data coding phase, reflexive excerpts regarding the researcher's reactions to and assumptions of the data were included; and these are made available in appendix F. As coding of the data was carried out, these were discussed in repeated meetings with the research supervisory team to identify themes in data and modify codes to create coherence and consistency.

During the analysis phase, awareness of the assumptions and interests brought by the researcher were addressed through inclusion of 'disconfirming cases' (Yardley 2015); this involves seeking deviant patterns or cases which do not fit with developing themes to present all the data, not just those that fit with researcher interest or viewpoint. Following analysis, a conversation was held via telephone to ask one participant for feedback (Silverman, 1993), check for meaning and importance, and to check whether findings accurately reflect the wider discourse within endocrinology. This was only carried out with one participant due to time constraints (of both the researcher and due to the busy schedules of this participant group).

A paper trail linking the raw data to the final report is included in appendix F-K to ensure transparency of how the interpretation was derived from the data (Flick 1998, in Yardley 2015, p.264).

Impact and importance:

Evidence of impact is often interpreted as a key indicator of worthwhile research (Yardley, 2015). The aim of this research was to explore the ways that Endocrinologists perceive and experience psychosocial and self-management support with regard to patients with hypothyroidism. The theoretical and practical implications for this research are addressed in section 5.6. (‘Implications for research and practice, and the role for Health Psychology’). This research aimed to elicit accounts from a group of clinicians, currently under researched in the literature and to generate useful knowledge and important contribution to the wider research conversation about psychosocial and self-management support.

3.3. Selecting thematic analysis as an analytic tool for qualitative data

Thematic analysis was selected in this research as the preferred method with which to interrogate verbal data and to identify and describe patterns of shared meaning across the data set (Braun & Clarke, 2019a).

Different approaches to thematic analysis exist throughout the literature. For example, ‘coding reliability’ approaches (e.g. Boyatzis 1998) are set within a positivist research philosophy but collect and analyse qualitative data, whilst ‘codebook’ approaches to thematic analysis are arguably located in a qualitative philosophy but retain some of the structure of the positivist approaches (Ritchie and Spencer, 1994; King and Brooks, 2017; Braun & Clarke, 2019a).

The approach selected in this thesis, reflexive thematic analysis, is specifically located within a qualitative paradigm that centres researcher reflexivity (Braun and Clarke, 2019b). It was chosen as the appropriate approach following the journey of paradigm change, and growing awareness of differences in values, attributions of importance, and identifying health models between the researcher and participants (as described in section 3.2. ‘Rationale for qualitative approach: Development of researcher’s epistemological and theoretical stance’), and because research exploring Endocrinologists’ views about psychosocial and self-management support for patients with hypothyroidism is currently unresearched. Reflective thematic analysis was chosen to enable generation of participants’ own stories and paradigms which may not have been previously defined by the researcher.

The flexibility of reflexive thematic analysis to be applied in a descriptive and exploratory way made it a suitable choice to meet the aim of giving a voice (Braun & Clarke 2013) to Endocrinologists whom we know little about with regards to this topic area. An experiential variation of reflexive thematic analysis (Braun & Clarke, 2013, p.175) was selected based on the ontological assumption of a partially ‘knowable’ world in a way which assumes language to represent the reality of the participant (Braun & Clarke 2012). This approach has utility to make actionable recommendations of use to practitioners, policy makers, or patients to create impact and importance (Yardley, 2015) and to achieve practical, real-world change (Rogers & Rogers, 1997; Yardley 2015). One example from a study with a similar focus was the development and evaluation of a training programme to enhance self-management support skills amongst Rheumatology clinicians (Dures et al, 2014b).

Reflexive thematic analysis was selected over alternative qualitative analytical approaches such as grounded theory (Strauss and Corbin, 1998) which is also theoretically flexible, and used within different frameworks to answer the different types of research objectives presented in this research thesis. Grounded theory was used by Dew et al (2018) with the Theory of Planned Behaviour (TPB) to organise themes regarding primary care health professionals' attitudes and intentions towards the treatment of hypothyroidism. However, grounded theory has greater utility to create theory about a phenomenon, rather than to generate experiential accounts (Braun & Clarke 2013, p.176) as defined as the primary aim of this research.

Whilst there is a strong online patient voice regarding the causes, symptoms of hypothyroidism and preferred treatments, little is known about the views and experiences of those who treat them from their own perspectives (as considered in Chapter 2 'Introduction and background literature'). This research provides an opportunity to examine the views and experiences of Endocrinologists in a way that values how they experience and make sense of the world (Braun & Clarke 2013).

Method

3.4. Design

This thesis adopted a Big Q, qualitative research paradigm to explore the beliefs, experiences, and practices of participants (e.g. Kuhn, 1962; Kidder and Fine, 1987).

Participants were recruited to participate in semi-structured telephone interviews of 30-45 minutes duration.

Reflexive thematic analysis (Braun & Clarke, 2019a) was used for data analysis, employing an experiential orientation (Reicher, 2000). Verbal data was interrogated semantically (descriptively) to summarise the data.

3.5. Ethical approval and conduct

Full ethical approval for this study was granted by the University of the West of England (UWE) ethics committee (UWE REC REF No: HAS.18.10.038) following satisfaction of all conditions relating to 'ethical conduct of research involving human participants'.

Further updates and training were provided through the UWE 'information security toolkit' as part of the Professional Doctorate in Health Psychology 'Professional Skills' module to ensure that the research remained in accordance with the updated 'General Data Protection Regulation' (GDPR) which replaced the 'Data Protection Act' (DPA) as the law governing the processing of personal data on n 25 May 2018.

3.6. Sampling and participants

Participants were 18 Consultant Endocrinologists (3 females, 15 males) from the United Kingdom with experience in the treatment of patients with hypothyroidism with persistent symptoms.

A snowballing sampling technique was used to approach Endocrinologists to take part in semi-structured interviews. To initiate this, the British Thyroid Foundation were approached to recommend one Endocrinologist. In turn, they were asked to contact and invite two more and to pass on the researcher's contact details. Following initial contact from those who wanted to take part (or after permission was given to contact potential interviewees by previous interviewees), potential participants were emailed an information sheet and consent form (included in appendix B and C).

During this process, one female Endocrinologist declined to take part (giving 'being too busy' as the reason), and two additional male Endocrinologists did not respond to the invitation to take part from their colleague. Another participant agreed to take part but was unable to schedule an interview due to time constraints. Through this method, the intended sample size of between 6-15 interviews to provide sufficient data for a UK professional doctorate project using thematic analysis (Braun & Clarke 2013, adapted in Terry et al, 2017) was exceeded. By the 18th interview, being guided by the principle of data saturation, it was judged by the researcher and supervisory team that no new data was being generated by participants' accounts. A paper trial of data coding and theme generation can be found in appendix F-K.

Interviews were restricted to English-speaking participants. However, this did not skew results as this research is specific to the views and experiences of Endocrinologists in the UK who are expected to communicate with patients in English.

3.7. Information and consent

Potential participants emailed their intention to take part in response to contact through the snowball sampling process. At this point, an information sheet and consent form were sent and returned prior to the interview (a copy of these is included in appendix B and C). Potential participants were informed of the ways in which their data would be used and were directed to a contact at UWE for complaints about the research. Potential interview participants were reassured that no personal identifiers would be used in the reporting of this research. The interview phase involved the collection of names and personal data (i.e. gender, email address and employing hospital). However, in the data transcription and coding phase, participants were labelled 'Doctor A', etc. In the reporting phase, any identifying details (including place of work, or reference to publications) were omitted to protect anonymity.

Interview participants were informed on the information sheet that they could withdraw from the qualitative study without giving a reason. This was also reiterated in the debrief sheet (included in appendix E). Participants were informed that they could withdraw up to two weeks after the interview to allow suitable time to ask for further information or questions on the research after receiving the debrief.

The data gathered were participant consent forms (paper copies gathered before the interviews), and audio recordings of the interviews which were transcribed. Interviews were recorded using a digital audio recorder and electronically transcribed using Microsoft Word 10 (.docx). The audio recordings were password protected by folder and stored on a password protected UWE drive. Once the interviews were transcribed, the Microsoft Word documents were also stored on the secure UWE drive.

Paper consent forms were stored in a locked filing cabinet. Hard copies of the anonymised interview transcripts were also kept in a locked filing cabinet as a backup of the data but kept separately from the consent forms to ensure anonymity. No data was taken out to avoid theft or accidental loss. Audio recordings were only accessible to, and transcribed by the doctoral researcher, using headphones to avoid anyone else listening. The consent forms and interview transcripts were only accessible to the doctoral researcher via access to the locked filing cabinet. No participants requested to be withdrawn from the study, but participants were informed that if they wished to withdraw within the two weeks, the audio file would be immediately deleted without being transcribed. Once all the interviews had been transcribed, the remaining audio files were deleted after 3 weeks. Data will be kept securely on the UWE hard drive, and hard copies of consent forms and anonymised interview transcripts will be kept securely for 5 years. After this point, they will be securely disposed of in accordance with the UWE waste management policy in line with the UWE data management policy.

3.8. Minimising participant risk

It was not expected that any risk to participants would occur because of this research, as participants were not patients nor a vulnerable group. No deception was involved in this research and participants were fully informed of the research aims. Participants were informed of how to contact the UWE ethics department if they had any complaints about the research. Contact details of a named person at the 'British Thyroid Foundation' (BTF) was supplied in case any issues relating to practice arose during the research. The BTF were aware of the content of the research and this role in it. To minimise economical risks to participants, telephone interviews were deemed to be the most likely option to save time for the qualitative part of this research.

3.9. Data collection

The Interview topic guide

A semi-structured topic guide was developed for data collection (see appendix D). This was created from the existing literature (see Chapter 2 'Introduction and background literature' for an overview) identifying the support needs of hypothyroid patients, and complexities surrounding the treatment of persistent symptoms of hypothyroidism; as well as from the components of self-management (Lorig et al, 2003; and Mulligan et al, 2009, also used by McBain et al; 2018) also described in Chapter 2 (section 2.8. Reviewing the psychosocial and self-management support needs of patients with hypothyroidism).

During the design and testing phase, as the epistemological and ontological position developed, wider open-ended questions were included to explore participants' thoughts about the history of the treatment for hypothyroidism (see Chapter 2; section 2.4. The history of treatment for hypothyroidism). This reflected the developing awareness of the researcher of the practice and socio-political contexts of participants gained through engagement with collaborative consultation PPI activity (described in sections 3.2 'Rationale for qualitative approach' and 5.5 'Strengths and limitations'). It also reflected a growing awareness of semantic differences between medical and researcher paradigms gained through PPI activity, as discussed in section 3.1. ('Rationale for qualitative approach).

Questions in the topic guide were structured to elicit descriptions of clinical practice, as well as to include specific questions about the components of psychosocial and self-management (for example about helping patients to manage the emotional aspects of their condition and about meeting the informational and educational needs of patients) and also to enable participants to talk about the topic area using language from their own medical paradigm. The questionnaire schedule was therefore designed to be open ended and flexible enough to follow information salient to both the researcher and participants. The final question asked participants for any additional points they would like to add.

In order to review the qualitative interview topic guide for meaning and suitability, experts from the British Thyroid Foundation were asked to evaluate whether the questions were appropriate for use with Endocrinologists. No changes to the interview schedule were made because of this.

Interview process and reflections on interviews

Telephone interviews were offered to participants to minimise disruption to their schedules and because the geographical spread of participants reached throughout the UK. Interviews were pre-arranged to take place in a quiet time to enable adequate recording to take place. Participants were requested to return consent forms prior to the interview. Participants were given the opportunity to ask questions by email or immediately prior to the telephone interview. Participants were reminded (as on the information sheet) that they could withdraw from the qualitative study without giving a reason and this was re-iterated on the debrief form.

As the participant group were not patients or vulnerable people, it was not considered that they were in positions of vulnerability for interviews, however equal importance was given to the protection of participants' rights and confidentiality. Participants tended to partake from their offices after completion of clinics (around 2pm).

3.10. Process of Analysis

Analysis was completed following the 7-phase analytic process described below, taken from Braun & Clarke (2006) and Terry et al (2017). Whilst separate 'phases' are described for the analysis of reflexive thematic analysis, the stages are iterative and recursive with the researcher moving back and forth between the different phases (Terry et al, 2017).

1. Transcription

The researcher transcribed the interviews during the data collection phase.

2. Reading and familiarisation with data

This process is the entry point to analysis (Terry et al, 2017) and began during the data collection phase. It involved: reading and re-reading the data to become immersed and intimately familiar with its content; taking observational notes of items of potential interest and patterns; starting to ask questions about the data; writing notes in transcript margins, and using the highlighting function in Microsoft Word 10. During this stage, reflexive awareness was also important (i.e. noticing 'good' or 'uncomfortable' feelings in response to the views and attitudes of some participants, see section 3.12. 'researcher positionality' below).

3. Complete Coding

This phase involved systematic and thorough creation of meaningful labels or codes to reduce the data and organise it into patterns. It involved working systematically through the entire data set, noticing important features within the data and attaching a few words or a phrase to specific segments of the dataset of interest, or to those segments that might be relevant to answering the research question. Following this, the researcher used 'cut and paste' in Microsoft Word 10 to collate data segments (codes and relevant data extracts) onto clean pages for later stages of analysis. Following this, a list of codes was compiled that identified both patterning and diversity of relevant meaning within the dataset.

4. Forming and generating initial 'candidate' themes

This phase involved examining the codes and collated data to identify significant broader patterns of salient meaning (potential themes). This involved making choices about what data sets were relevant and what was important to say about them. The process involved examining codes (and associated data), combining, clustering or collapsing codes together into bigger or more meaningful patterns; and identifying features of relationship and similarity across different codes in order to cluster them together into a possible theme, and identifying a 'central organising concept' or idea that underpins the theme (Braun et al, 2015; cited Terry et al, 2017, p. 18). Thematic maps and tables were created to facilitate the process of shifting mapping of various patterns (Terry et al, 2017) and to understand the themes in relation to each other (see appendix G-J).

5. Reviewing and defining candidate themes:

Here, themes were shaped, refined, and/or rejected. This involved checking that candidate themes captured the meaning in the collated, coded data segments, and that within each theme all the data extracts were clearly related to the central organising concept (and that diversity of meaning around the central organising theme is captured); as well as checking that each individual theme is distinctive. It also involved reviewing whether the candidate themes worked well across the entire data set (not just the coded segments) to ensure that nothing had been missed, that to determine that the themes told a convincing story of the data, and one that answered the research question.

6. Defining and naming themes:

This stage progressed to an interpretive orientation of the data and centred on 'telling a story' based on and about the data; and making sense of the patterning and meaning (and diversity of meaning). The creation of short theme definitions (a summary of the core idea and meaning of a theme) helped determine clarity and scope for each theme (Terry et al, 2017) and helped to define whether there was enough depth and detail for each theme to stand alone as a key section of the 'analytic story'.

7. Writing up:

This final phase involved weaving together the analytic narrative and data extracts and contextualising the analysis in relation to existing literature (Braun & Clarke, 2013, p 202).

3.11. Researcher positionality

Research can be defined as 'a shared space, shaped by both researcher and participants' (England, 1994). The Oxford Dictionary (2017) defines 'positionality' as "the recognition and declaration of one's own position in a piece of academic work". This concept is important because in qualitative research, the personal values, identities and biases of an individual researcher can may shape the way in which they analyse data sets, and the resultant conclusions drawn (Bourke, 2014; Dean et al, 2018). Being explicit about our positions in our work allows those who read our work to better grasp how we produced the data (Finlay, 2002).

In Section 3 'Methodology' and section 4 'Methods', I have outlined the ways that I have approached this research; the epistemological and ontological positions and the shifts that occurred through the research development and testing phases of this research. In this section, I consider how my interpretation of the social world impacts how I approach my participants, my analysis, and the conclusions I draw.

As noted in section 3.2.' Methodology' the rationale for this research came from my work with the British Thyroid Foundation (BTF), which drew my attention to the 'problem' of patients with hypothyroidism experiencing persistent symptoms. This led me to carry out a systematic review into the existence and effectiveness of psychosocial and self-management interventions to address identified need in the literature. However, I found very little in terms of support in this area and I embarked on a consultancy project with a Clinical Professor in Endocrinology and their department to explore how they addressed these issues in their own practice with a view to informing my own work. This resulted in my discovery of issues around patient 'dissatisfaction' regarding a lack of access to person-centred medical treatment approaches and debates in the field regarding the patient group themselves, the causes of persistent symptoms; and the necessity, safety and cost implications of treating them according to the symptoms and lived experiences reported in the literature.

I am a 42-year-old British woman, with mixed race heritage. and a mother of two. I have a BSc in psychology, an MSc in Health Psychology and I am a Stage 2 Trainee Health Psychologist. My research interest primarily focuses on the application of health psychology theories, models and tools to issues surrounding health and illness. My identification with the biopsychosocial approach (Engel, 1977) has played a role in my focus in multidisciplinary approaches to health which reject the mind-body dualism which underpins the treatment approach to many long term conditions and advocates for integrated care and integrated care (e.g. Johnson. 2012).

I have experience of supporting people with long term conditions and have worked in NHS and charitable sector positions in the areas of CFS/ME (chronic fatigue syndrome), cancer and COPD; and finally in a voluntary position with the British Thyroid Foundation. I have helped patients to adjust and cope to their illness by providing information, education, and psychosocial support (e.g. CBT) and have facilitated health promotion and peer support groups for patients to develop self-management skills. I initially approached this research from a ‘patient advocate’ position with the belief that collaboration between health psychology and medical paradigms (and others) may help patients struggling with their thyroid condition to develop the skills and confidence to manage their health, and to reduce psychological distress.

Whilst I was not directly an insider-researcher (i.e. a doctor), I collaborated with an endocrinology department (in a specialist thyroid clinic) and understood that my skills and experience were valued by the doctors I had worked with. My doctoral level training and experience of the patient group enabled prolonged engagement with and immersion in the topic area. However, as a doctoral trainee, I initially worried that I lacked expertise, particularly around medical terminology and procedures and this affected my confidence in the initial interviews, leading to me sticking rigidly to my interview topic guide. My position was therefore different to other qualitative research where the researcher may be in a position of authority or power over participants. As my experience and confidence grew, I became more relaxed and felt reassured by the responses of participants to talk to more openly to them about the topic area. This led to more open and conversational interviews and enabled me to follow the narratives of participants more freely.

After each interview, I wrote notes in a journal to explore the key issues and the way that I felt. I recorded the ways that I have brought my own knowledge of health psychology to the interpretation of the verbal data of my participants. However, my use of an inductive analytical approach aimed to avoid being constrained by pre-defined knowledge and frameworks. In the final interpretive stages, however, I have used my knowledge of appropriate areas of health psychology to help me to tell a story about the data collected.

Chapter 4: Findings

This chapter presents the analysis of data from 18 Endocrinologists regarding their views and experiences of psychosocial and self-management support for people living with hypothyroidism. No demographic data relating to participants is presented in this chapter for issues relating to confidentiality. The Royal College of Physicians 2018-2019 census of UK Consultants shows that there were only 1,089 Endocrinology Consultants across all 1,257 hospitals in the UK. Therefore, all identifying data was removed from this study due to the potential for identification.

Four overarching themes, containing twelve subthemes were identified following examination of the data using reflexive thematic analysis. These are presented in the table below alongside the thesis objectives. A poster summary of this thesis with an emphasis on the findings can also be found in 'Appendix M: Poster presentation of findings'.

Thesis objectives and Overarching themes	**Subthemes**
Endocrinologists' views about the psychosocial and self-management support needs of patients living with hypothyroidism: Theme 1: Walk with them	Patient heterogeneity
	Diverse support needs
	Will, skill, and confidence
Do Endocrinologists refer patients with hypothyroidism for additional psychosocial and self-management support? Theme 2: Embedded is best	What we do
	Professional identity
	Difficulty shifting the focus
Perceived facilitators to the implementation of psychosocial and self-management models of care: Theme 3: Incorporate and collaborate	Patients first
	Seamless care
	Assets and strengths
Perceived barriers to the implementation of psychosocial and self-management models of care: Theme 4: We can't do this alone	Funding
	Research
	Culture change

4.1 Overarching theme 1: Walk with them

In this first theme participants identify that patients with hypothyroidism have diverse needs for psychosocial and self-management support and require professionals to 'walk with them' from the point of diagnosis but that participants report varied will, skill and confidence to meet these needs.

Subtheme 1: Patient heterogeneity

Participants identified heterogeneity amongst patients living with hypothyroidism and diversity of support needs amongst patients with persistent symptoms. Participants firstly identified that many patients suffer with persistent symptoms of hypothyroidism as a result of suboptimal thyroid hormone replacement in primary care settings.

Doctor C: *"the reference is rather wide. You might need to treat the dose further and try and get the best, or the optimum outcome"*

Doctor N: "I think based on the literature, both overtreatment and undertreatment are common, and it is not just in the UK, it's all over the world"

Two thirds of participants (eleven) also identified that patients may present with additional symptom burden resulting from autoimmune thyroid disease as the underlying cause of hypothyroidism.

Doctor R: "I wonder about autoimmunity; rather the chronic inflammation in the gland plays more of a role than we really recognise uh and I wonder whether that contributes to the symptoms"

Doctor F: "the mere fact of having an immune reaction the inflammation, is that leading to sense of unwellness to the release of cytokines (…) cytokines make you feel you know, that you've got the flu"

Doctor G: "but majority of them are autoimmune patients (…) whether it's just autoimmunity itself or autoimmune hypothyroidism which is causing all these symptoms"

Seven (nearly half of) participants also raised the additional support needs of patients with hypothyroidism as a result of treatment for thyroid cancer.

Doctor N: "I think especially the people who have got cancer, there are other reasons not to feel better"

Doctor C: "because they've had thyroidectomy surgeries, and a high dose of radioactive iodine therapy. It could then yield them completely hypothyroid"

Doctor R: "the people who have had surgery for thyroid cancer"…"I would let them know to make sure that they have enough calcium in their diet and to properly supplement with vitamin D, and make sure they get weight-bearing exercise"

Participants also felt that persistent symptoms of hypothyroidism in some cases are attributable to undiagnosed physical co- or multimorbidity:

Doctor Q: “some of the symptoms of hypothyroidism are very non-specific so you have things like tiredness, brain fog, lethargy which you can have in many other conditions”

Doctor B: *“I would very much want to rule out organic disease”*

Doctor C: “checking for vitamin D deficiency, cortisol levels, other potential causes for fatigue or whatever the symptoms might be, they sometimes, they just throw up an answer”

Participants identified that presentation of persistent symptoms may be a result of patients having medically unexplained symptoms (MUS), or conditions that are not adequately explained by current scientific knowledge, having been also diagnosed with subclinical hypothyroidism, which may not have been the cause of presenting symptoms:

Doctor P: “people can get those symptoms for a whole variety of health reasons and also a lot of psychological and functional reasons that are not due to hypothyroidism”

Doctor B “some patients who actually their symptoms are not related to the thyroid their symptoms are quite vague especially if they only have very mild changes”

Doctor N: “there'll be patients who might have borderline thyroid dysfunction and were started on levothyroxine and for this reason they never felt better”

Doctor F “we just have to accept that there is a group of people who've got medically unexplained symptoms”

A group of patients who may experience persistent symptoms due to individual responses to treatment, for whom standard LT4 treatment may be ineffective were also described. All participants agreed that scientific unknowns, and ongoing debates exist regarding the cause and prevalence, and regarding management strategies for this group as identified in Chapter 2.4. (‘The history of treatment for hypothyroidism).

Doctor P: “well, there may be something in there, maybe they don't at the tissue level convert T4 to T3”

Doctor B: “*I would like to think there is a T3 responsive group and there is a non-T3 responsive group, if you want to look at it that way””*

Doctor C: “*there might be this individual variation that not everybody on thyroxine might be affected to feel that normal”*

Subtheme 2: Diverse support needs

Along with diversity of patient subgroups, participants described a diverse range of support needs presented by patients in secondary care. These included managing weight gain, mental health issues, poor quality of life and cognitive difficulty:

Doctor L: "A lot of these patients, they complain of weight gain or difficulties maintaining weight"

Doctor P: "these individuals will generally score higher on anxiety and depression scale"… "symptoms of hypothyroidism is fatigue and another is the brain not working properly"

Doctor O: " there's that whole underbelly of mental health problems just related to the burden of trying to manage a chronic condition all the time and requiring a high level of self-management skills which many people don't have"

Doctor G: "I have patients who've gone back to work, who started back in university, whatever to complete their studies or somebody who was very good in music, had stopped feeling the music, feeling doubtful"

Doctor B: "they can't think straight, they can't concentrate, they can't perform well"

Participants felt that patients require education and expectation management from the point of diagnosis to help them to understand that not all symptoms relating to hypothyroidism can be resolved with thyroid hormone replacement therapy (e.g. inflammatory symptoms of autoimmunity), and that mild biochemical changes detected in blood tests may not be the underlying cause of presenting symptoms. A lack of expectation management was highlighted as a particular cause of patient dissatisfaction with treatment.

Doctor C: "a lot of the time, it is expectations of treatment rather than actual uh the medication aren't really working."

Doctor A: "I think patients build their hopes up and of course they seek a treatment and the GPs will I think listen to that because a significant proportion of them are not knowledgeable about thyroid diseases and they will collude with the patient and say "Yes, here's the answer, here are some tablets you'll be fine"

Doctor O: "I think it is that expectation management early in the condition that is quite important I uh I think often people have been struggling with these symptoms for quite a long time and they've been consulting for quite a long time. For someone to find something that's abnormal, often um that's grasped onto (…) but probably wrongly, but you then set up a trial that goes on *for months and years ahead"*

Doctor A: "your expectations might be that you'll be back to your normal self-overnight and that's not going to happen"

Doctor C: "the challenges are around how we manage expectations, how a number of people being started on thyroxine treatment year on year in the UK and obviously, worldwide potentially."

Subtheme 3: Will, skill and confidence

When asked about the ways in which participants addressed the psychosocial needs of their patients; not all felt that they were equipped to do this in an optimal or structured way. Not all participants felt that this was part of their clinical remit, whereas others described this as a central part of their role.

Doctor N: "I feel reasonably confident to identify or probe when I think a patient is struggling"

Doctor G: " I wouldn't say that I'll be able to support them adequately because it slightly lies out of the clinical remit but what we tend to do is or I tend to do is refer them to their GP and highlight these issues that they'll need supportive therapy"

Doctor A: "I think I'm not sure the way I do it is optimal but I can describe to you what I do if you wish uh but I'm pretty certain that generally both GPs and Endocrinologists don't do this well and (…) I think that may well explain the dissatisfaction with the care that all these people get"

Doctor I: "what is relevant is having a proper discussion with them and getting them to understand their condition (…) and ruling out other causes for these kinds of issue guidelines and that's the most (…) I don't think I have skills and stuff like that come into play uh I don't think it's relevant"

Doctor A: "I don't think I have the will really to sort of change my professional approach."

Doctor O: "I think it's just that we don't have the capacity or the support services, or probably the skills, but mainly the time"

However, the need for psychosocial support was considered key in the healing process amongst participants who expressed willingness to engage in addressing patients' psychosocial needs.

Doctor G:" I think that's the huge gap what we have not only just with thyroid even with patients with any chronic conditions, diabetes as well (…) they should have that support actually *psychological support is very important ongoing support because it's not easy to manage these conditions day in and day out and not burn out (…) that burnout has to be recognised but I don't think we have a service at the moment which can deal with the sort of things that they need because it's not only just about one day, it's about walking with them because this is a lifetime condition (…) any chronic conditions they need that ongoing support because there will be times when they'll be low, they'll come to a point they would like to give up everything like ' I'm not bothered anymore' so those are the times when they just need the support so that they can carry on and then take the baton again back in their hand"*

4. 2. Overarching theme 2: Embedded is best

This second theme encapsulates participants' attempts to explore psychosocial issues and embed components of self-management support in their practice but highlights subsequent challenges to professional identity. Difficulties in shifting the focus of the consultation are reported and are perceived to be fuelled by a battleground around access to LT3 and a lack of available service provision.

Subtheme 1: What we do

Participants described giving patients time, listening to their concerns, and building trust as key elements of their role during the consultation with patients.

Doctor A: "One of the most precious parts of the relationship is trust"

Doctor C: "trust I think is the other thing because I think if they start trusting what you're saying rather than (…) until then because until then they'd been trusting the online blog"

Listening without judgement to validate patients' input was considered a valuable start to the healing process.

Doctor F: "You sit down and you go through everything and you do it properly in front of them and you don't short-change them with time (…) you listen to everything they say and uh you read everything that they've provided. You give them a lot of detailed explanation and you follow that up"

Doctor C: "for most patients, it's just listening to what they're saying that's an important asset to the whole thing (…) they feel like somebody's listening to what they're saying. A lot of the time from the patient's point of view and again, I think it's down to the fact that for GPs is just a rushed conversation for obvious reasons and they might even just be coming out with a second symptom *and the GP might say "that's fine we'll just prescribe this or I'll do this, that or the other". The patients feel that they're not being listened to, I uh think just the fact that somebody's listened to what they're saying and understanding what they're going through I think is an important factor, secondly then spending time explaining how thyroid hormones work"*

Participants felt that many patients have fought for their diagnosis and to have their voices heard and some emphasised the importance of not being perceived by patients as part of the problem.

Doctor B: "a lot of people that I see are very angry have fought for a long time trying to get a hold of drugs etc. Just giving them the opportunity, listening to them, helping them discuss instead of saying, "The answer is no. What is your question?" you know, It's immensely helpful (…) it's an enormous relief for the oh people that they can actually stop fighting and start healing if you want to look at it that way."

Doctor D: "most of that is because they feel that there's a battleground out there and uh as I'm not a battleground it's not that difficult because actually for the first time, they've got somebody that says, "Well, I'm not going to argue with you, I'm not going to say your blood tests are perfect, you should feel well."

Participants described their role in educating patients to support their understanding and to increase adherence to treatment.

Doctor F: "I don't have any graphical slides that I routinely use but I often draw a thyroid gland on a piece of paper, and I draw pituitary, gland and I explain the feedback mechanism and how to interpret the function test, but there isn't a specific additional tool that I use"

Doctor J: "I don't really see enormous differences in times between educating doctors and educating patients you know if you want people to do the things that you think are in their best interests, you have to persuade them and convey to them that this actually truly is in their best interests (…) that means time and a full explanation"

Doctor A: "I think it's a process of trying to impart good quality information about the condition and its treatment and to explain to them (…) what you know my strategy is"

Some participants described offering trials of LT3 therapy, on its own or in combination with LT4, whereas others did not due to safety concerns. Some did not feel that there was sufficient evidence to support the use of T3 and highlighted risk to patients as a cause for concern. Those who did, emphasised the importance of managing patient expectations through goal setting and action planning for patients to understand that this may not be the answer to the symptoms.

Doctor K: "I also make it clear to those who are using it that it is a time limited trial of treatment, usually six months trial"

Doctor C: "It's a never ending process if you don't have an agreement right at the beginning"… "You could go down you know this route forever. I think what I find is have boundaries, manage expectations right at the beginning and have an agreement."

Participants described attempts to promote healthful behaviour during consultations but felt that there was limited condition-specific evidence for them to draw upon, which reflects findings of the systematic review presented in chapter 2.5 ('Systematic review'). They described more confidence when considering medication interactions to increase biological treatment outcomes but less so in promoting specific behaviour changes.

Doctor J: we know that if you combine iron or calcium and vitamin D with thyroxine replacement you will dramatically reduce its absorption I think those bits of education should be done by all clinicians for all patients"

Doctor L: "For me it's usually the general lifestyle advice that I give to patients (…) now a lot of these patients who come in who are struggling are already doing those things because they've worked from first principle and are doing that but I just reiterate the advice really"

Doctor B: "I'm tempted to just say to the patient, "For whatever you feel gives you more energy, so long as it's not going to be harmful, I would strongly be supportive of." Some people, they do a little bit of breathing exercise, I'm not sure that's a big thing. A few people engaging in other complementary therapies. Some people try meditation or mindfulness. I don't think I can identify one specific one. My rough shot at it is it is a more holistic listening and supportive approach"

Doctor N: "Clearly, the exercise seems to improve or make them feel well, that's something I tend to encourage, but I'm not 100% sure whether there is a study. Do you know of anybody?"

Subtheme 2: Professional identity

Participants mostly described openness towards approaches in which patients use multiple sources of support to address their wellbeing. However, difficulty was highlighted by some participants when this included patients requesting or self-sourcing non-standard alternatives to LT4 therapy (i.e. T3 or NDT). This was a common area of concern and worry, which introduced doubts about the concept of self-management within hypothyroid patient groups.

Doctor F: "I think there certainly is a degree of self-management like there is in any condition really and lifestyle is part of that. It's different from something like diabetes where you may have *to self-manage the dose that you gave. I think dose in a in a lot of these patients, they manage the doses themselves depending on how they feel, and that, if anything, makes it more difficult for us to assess what their status is because we're not actually really sure what they've been taking and how to interpret their results just in light of that"*

Doctor F: "there may be a degree of misinterpretation or misunderstanding by patients who don't have the same training as doctors"

Some clinicians were more open than others to support and monitor patients' use of non- standard treatment choices. Others felt that safety concerns and 'scientific unknowns' posed a more significant problem for the collaborative doctor-patient relationship, especially for clinicians who do not feel confident in the use of T3 or NDT.

Doctor L: "If they go and buy things on the internet, then often I have that conversation with them that I say, "look, I need you to take what I suggest and what I prescribe or whatever in combination with what your GP prescribes. If you then go and buy things on the Internet, then that really makes it difficult for me to manage because I can't help in that situation because I don't know what I'm dealing with""

Doctor A: " I'm concerned about the safety of combination treatment and that on this basis I don't recommend it."

Doctor G: "the patient would like to try it, but not all the physicians would like to trial it. That makes no sense to the physician a because not everybody believes in T3 and NDT. When you don't believe there's no point in trying it because I can't send some of my physician colleagues who do not use T3 because they don't believe in that concept"

Participants described feeling stuck in the middle between shouldering personal responsibility for risk and patient safety, and not wanting to contribute to anger and perceived polarisation between patients and the healthcare system. For many, this was a difficult position to be in, due to the potential risks of overtreatment with thyroid hormones (particularly T3) which may include atrial fibrillation and osteoporosis in the long term.

Doctor H: "Basically what I say to patients, "If you're taking the desiccated on your own I'm not prepared to take any form of clinical responsibility." I'll supervise it, but I won't take clinical responsibility if anything goes wrong with that, if you know what I mean."

Doctor Q: "the clinician must be happy to initiate T3 and if the clinician is not happy to do that, there is nothing compelling that clinician to do so"…"even if the patient met the criteria in the *guidelines for T3 and the clinician wasn't confident or happy to give that prescription, that that position is perfectly valid"*

Doctor Q: "I think the average Endocrinologist would feel out of their depth, sometimes to prescribe T3, only because they don't have any experience really"

Doctor K: "If they are prepared to accept those risks then I will say they (…) because they feel so much better about that then I'd say you can continue if you accept the risks"

Doctor D: "we have to have a few simple ground rules and make sure that you're safe because I do say there aren't that many people as an Endocrinologist that are happy to do what I'm doing so I'm putting my head above the parapet."

Some participants reported that the current situation negatively impacts upon their own job-related satisfaction. This was particularly true for those who felt in a difficult position as patients' last resort after unsatisfactory attempts to manage hypothyroidism in primary care. They described a lonely task of 'plugging the gaps' left by scientific unknowns, cost restrictions and unrealistic patient expectations regarding the tools available to Endocrinologists to address their symptoms. Others however, felt more positive and engaged in moving the situation forward. This was particularly true for those working in a specialist thyroid environment who felt supported by clinicians with a similar specialist interest, and were actively involved in research in this area.

Doctor O: "*I think probably most of us have a single consultation and it's relatively short and I think you often come into it with a bit of trepidation because you kind of know what's coming."*

Doctor A: "If you're an Endocrinologist and you get a referral from the GP that states all this, your heart sinks, okay? It really does, because it's a difficult problem (…) you reflect on your own previous experience of how frustrating it is, unrewarding to feel this. I can understand why lot of colleagues in the end really feel negative about it"

Doctor Q: "those of us who have a particular interest in thyroid and in hypothyroidism, we are not so concerned and I speak for myself what I suspect is the same for colleagues, we know what to expect"

Doctor B: "I'm reasonably comfortable trying alternative options because at the end of the day, it's only a trial of other forms of common replacement that will tell you which group they fall into"

Subtheme 3: Difficulty shifting the focus

Participants felt that many patients arrived at consultations with a fixed agenda of what they want. They noted that patients with hypothyroidism were generally an activated patient group but that they are vulnerable to misinformation which contributes to rigid beliefs.

Doctor R: "I think people, because they feel unwell well they'll obviously have been online and they may already come to me with very strong views about T3"

Doctor C: "all they have heard are those stories online how T3 has changed my life."

Doctor P: "I mean, again, to be fair to this group of individuals, they've generally been through all that themselves before. I think they are an extremely well-read group of people by and large. In my opinion, a lot of the stuff they're reading is very inaccurate, biased, and feast on anecdotes rather than hard scientific evidence"

Participants described their role in helping patients to look for other reasons for their symptoms, or to correct fixed beliefs that LT3 therapy will be the answer to their persistent symptoms.

Doctor J: "I don't think patients themselves believe or sometimes considered that there might be something else genuinely behind this. I think by the time we see them is often the next massive focus on the fact this must be thyroid hormone not working. Whilst that might be the case, it might absolutely not be the case. If you're looking under the wrong cushion, you will not find what you're looking for."

Doctor P: "I think I could I could spend all day with some and it wouldn't make any difference"

Doctor C: "I always say to patients is that actually by focusing so much on the thyroid, they're doing themselves a disservice by taking their eyes off other potential reasons for the symptoms"

However, participants described difficulty shifting the focus of consultations away from discussions about biological treatments (T3 and NDT), particularly when they tried to consider psychosocial factors which may be contributing to their overall health and wellbeing status.

Doctor B: "I do discuss other features that are going on. The patients in general don't want to talk about that they say. They want to focus on the biological elements. We all have discussions about other stuff that's going on for them, discover what might be other major stresses in their life, financial, bereavement, relationship, that kind of thing. They need to be aware of that and continue to discuss those things, continue to encourage them to work on those sides as well as on the biological side. That's partly if you like a bit of expectation management there too."

Doctor F: “Patients feel stigmatised by the diagnosis of depression even though medically speaking there’s nothing wrong with the diagnosis at all, of course. Equally, medically, unexplained symptoms simply mean we don't have an explanation for them it uh doesn't mean to say, "It's all in your mind. You're making it up" It just means to say "We don't know why you've got these symptoms”

Doctor P: “again, these individuals have very, very fixed beliefs. If you start saying, actually, I think this is more psychological, they don't like that”

Participants felt that many patients viewed hypothyroidism as an acute condition which is responsible for all present symptoms, and that they held expectations that their symptoms should fully reside when they found the correct treatment (which may be T3 or NDT if symptoms did not reside with standard T4 treatment).

Doctor R: “sometimes the consultation could have start in a bad footing because they have one thing in mind that they want and if they think that they're not going to get that they get upset, pretty quickly”

Doctor Q: “we're still in an era where people come to you and they want a drug they want a treatment and if you cannot offer them a treatment it's assumed you've failed”

Participants identified patient perceptions of distrust and disregard, and an ‘us and them’ divide, developed prior to the consultation from previous experiences and from sentiment shared with similar others online:

Doctor R: “sometimes they expect a very hostile response which I usually don't give a very hostile response, but they might have just had some other health professional so their guard is very much up”

Doctor Q: “there are patients who come with the us versus them idea in their heads and you are like the enemy before even you say a word”

Doctor F: “you're tarnished before you talk”

Participants described difficulty and dissatisfaction when they could not solve patients’ problems with the available tools and treatments. They described a lack of available services to refer patients in this situation to, and that many did not feel happy or skilled in the situation of leaving patients ‘in limbo’.

> *Doctor D: “usually by that point people are already in a healthy diet they’ve looked at ways to enhance the diet and exercise to manage the fatigue, they've seen lots of people already”*

> *Doctor P: “that other explanation may not be a physical explanation and you know lot of people they don't want to hear that or the next question is then ‘What can I do to help myself?’ and then we have a discussion about the lifestyle they say ‘well I have done all of that that stuff already’ and you know it's a very unsatisfying consultation by and large I have to say”*

> *Doctor O: “people come wanting one thing and they end up feeling that they're not getting it and that you had a quite difficult consultation and you don’t feel feel like you've been able to help that person very much. It's all very difficult”*

> *Doctor O: “I think it's always difficult when you can't quite always explain why people feel like they do. It becomes quite difficult. I think if you've gotten an explanation, it may not always work, but it's often more helpful than when you're saying, "Well, it's not this, but I don't know what it is" I think that's quite difficult because you're just leaving that person in a bit of limbo”*

> *Doctor E: “where I find it more challenging is when people go and their lives are still horrible or where we’ve given them a trial of T3 and they’ve got to the edge of what I call their comfort zone and we’re between the devil and the deep blue sea and that makes me feel quite unhappy”*

Participants felt they had to be careful not to inflame feelings which could be construed as dismissal or disregard. Most participants were committed to trying all they could but felt that patients expected them to remain focused on endocrine pathology (also see section 4.3. ‘Assets and strengths’).

> *Dr Q: “Sometimes we can send to a dietitian or prescribe regular exercise but in doing that we have to be careful because it can be misconstrued by the patient again as dismissal”*

> *Doctor Q: There are still divided opinions, lots of divided opinions but one thing I believe them that such a group exists. If you look at the latest guidelines”… “there’s a nod to these patients that yes, some patients may still not feel well, some patients may still not feel well but 10 years ago such patients were considered unhinged”*

> *Doctor R: “If they've been dismissed by an Endocrinologist before, they would feel all Endocrinologists don't care and they're just there to get them away.”*

Participants who described ‘keeping the door open’ to biological explanations for persistent symptoms were more likely to offer therapeutic trials of LT3. These participants felt that validating patients’ beliefs about treatments, and ‘turning over all stones’ to eliminate all biological explanations gave them more of a mandate to explore psychosocial issues with patients after therapeutic trials.

Doctor D: "I feel very relaxed about it. I used to, and I think as Endocrinologists we can be sort of somewhat black and white and dogmatic about it, I mean, we've all struggled with that group of patients over the years, and none of us know how best to help people"…" Now I sit on the fence and say I don't know but say to the patients, "I'm not here to say you can or cannot have a particular treatment"”

Doctor B: "what people they benefit from is listening and an explanation and keeping the door open that there may be a biological explanation. Basically, that actually relaxes people a little bit to consider other things because it's like, "If you think I'm mad, I'm not going to have a conversation with you," but if I give them the legitimacy which I think is legitimate, that there may be a biological reason why they're not feeling well. That helps me engage more with other aspects. It gives me a bit more of a mandate to discuss those things."

Doctor G: they would like to try something different and see if it works before accepting the fact that is not probably all hypothyroidism and this could be something else going on. Then did a little bit deeper into their own lives and say, okay, stress, our lifestyle or work could be a contributing factor"

Dr J: "sometimes you can't give the patient an answer (…) this area is a classic example I can look under every single cushion turn the room inside out and still not be able to explain to the patients at the end of the day why they don't feel right but if at least I say to them "I've looked everywhere I can think of looking" patients often appreciate that even if you haven't absolutely solved every problem they have"

4.3. Overarching theme 3: Incorporate and collaborate

This third theme ('Incorporate and collaborate') presents an overview of participant-perceived facilitators of psychosocial and self-management support. It presents participants' views that asset-based collaboration is required to address gaps in provision in primary and secondary care. Valuable partners include: Patients, Endocrine Nurses, Health Psychologists, Pharmacists, Exercise Physiologists, embedded Researchers, and experts in the charitable sector.

Subtheme 1: Patients first

Participants held different opinions about the categorisation of hypothyroidism as an acute or chronic condition. Those who viewed the condition as chronic were more likely to hold attitudes that patients should be involved as partners in their care.

Doctor A: "people that have hypothyroidism and symptoms from it should return to the normal state of health after they have been treated".

Doctor E: "some people find it very straightforward and don't have any problems and others find it much more challenging to manage"

Participants with a 'chronic condition perspective' highlighted the importance of including and incorporating patients as respected partners; to solve problem with them and not for them; and not to reduce patients to passive recipients of care:

Doctor A: " you've got to actually engage the patients in the process of trying to answer this question. What is it that you expect? I don't think that they understand it terribly well and I think that can be variable within one patient from one time to the next"…" I think the crucial thing about it is you've got to get the patients involved right from the start."

Doctor B: "I think that increasingly helps people feel that they're not being fobbed off and hidden to as well as trying to feel that they're being respected partners and understanding this process"

Doctor N:" I think it will be helpful to see them and see what are their fears and concerns and where they're coming from. I'm not sure just giving a leaflet would alleviate it"

Doctor Q: "I think the changes are occurring. Five, 10 years ago, anyone who was unwell still on thyroxine would be completely dismissed there would be no discussion about it, your TSH is normal and that's it but now we recognise that such a group exist and we are beginning to see them and trying to understand them."

Participants highlighted the growing use of patient reported outcome measures (PROMS) to capture patients' perspectives about clinical treatments for hypothyroidism and reported increasing interest in condition-specific PROMS for Clinical Commissioning Groups.

Doctor H: "we've actually just started doing locally now, because the CCG is clamping down on T3 is doing some (…) I'll call if you'd like questionnaire, before and after. We've got a (…) we need to document a definite clinical improvement whether that be physical or psychological in order to continue with T3"

Some participants were onboard with PROMS and felt that their use should be widened to encapsulate the patient voice in a wider context to understand and address a broader range of health outcomes.

Dr J: "I think that probably the endocrinology with patient-reported measures. I think of the patient reported measures at the moment, the big problem we are having in endocrinology is that our questionnaires and our patient reported surveys, etc suffer from the lack of specificity if I can put it that way. What I mean by that is that the symptoms and sometimes the features that will be recorded in those might not just be a feature of having suboptimal replacement, they might be capturing other features and things in life as a whole. I think we need general disease-specific questionnaires as best as we can, together with quality of life questionnaires. Understanding whether somebody could have depression is really important because if they could when you keep fiddling with the thyroid hormone, you'll never make them better"

However, other clinicians reported scepticism about the role that patients should play in reporting their own health status and expressed distrust of non-medical biomarkers of health.

Doctor K: "the problem is that I think people on combination treatment if you ask them to do patient-reported outcomes, would report better outcomes if they want to carry on the combination treatment. I think it's quite difficult to remove bias from those really. I am always very happy to look at them, and I know they're planning to develop a new tool to support the NICE guidance. I keep an open mind should I say, but I don't use them in my practice."

Doctor L: "I think the further development of thyroid-specific questionnaires, just like the THY-Pro I'm involved in a project where they're trying to see if we can get the THY-Pro put into an online version that then can be used by clinicians in clinics. (…) essentially, I think that is the way forward, my, my colleagues tell me that "I can still predict how they're going to fill this In", but then that is how that patient group feels, so that's what we have to take seriously".

Doctor D: "anecdotally, the vast majority of patients seem to feel a lot better on it."

Doctor I:" I don't like going on anecdotal evidence from individuals"

<u>Subtheme 2: Seamless care</u>

Participants felt that much of the patient dissatisfaction stemmed from suboptimal treatment originating in primary care (see section 5.1: 'Patient heterogeneity') and highlighted a need to engage and support patients from the earliest point. However, participants identified a gap in service provision at the interface between primary and secondary care. Participants felt that intervention targeted here may better manage patient expectations and stem the flow to secondary care.

Doctor R: "I think if people are properly counselled at the start that perhaps they wouldn't be so disappointed later on if they didn't see any major changes."

Doctor O: "I think having something a stage I think between primary care and ourselves would be a good idea, I think. It almost feels like sending someone to an Endocrinologist, it's sort of saying, "Yes", and escalating it and confirming it even further whereas if some sort of exploration of (…) I think that the biochemistry is important why it might not be the thyroid or what other things we might look at. There uh maybe isn't always a disease and perhaps, there are other things like coping skills and actually it may come down to managing symptoms and how people do that rather than saying we're going to (…) almost like a chronic pain approach"

Doctor F: " I think there's an absolute crying need for support for these people and that could be GP based. That's where it is. That would stop many of the referrals to hospital which are ill-equipped to deal with and you get the two flowing backwards and forwards."

Doctor C:" the other possible way of dealing with this would be to empower, train people, either nurses or specific GPs with a special interest in primary care to be able to deal with this within primary care within each health area, CCGs or geographical areas"

Subtheme 3: Assets and strengths

Participants described limits to the capacity of what they felt they could achieve within consultations. They felt that additional skills sets may bring value to meeting the diverse needs of patients with hypothyroidism.

Doctor F: "We don't have in hospitals a sufficiently good and available health psychology service. If there's one thing I would like, I'd like to see much more of that available"

Doctor G: "Having a psychology service attached to chronic disease management will be helpful"…"sometimes the patient might attribute all the symptoms to hypothyroidism but in fact they don't know what they do, not able to cope with the other life events that are happening and there is an overlap there"

Doctor B: "an Endocrine Nurse role along with a Health Psychologist role here. It's a balance between dealing with the organic and the less explained. I'm reasonably comfortable at managing the medication, adjusting the medication, discussing the issues. It would be helpful to me, I could see more patients, if, for example, there was an Endocrine Nurse who said exactly the same thing *but went into it in more detail"…"It's more of a health psychology role to go into the wider aspects of their life and how they can get a better outcome overall by addressing other aspects of their life."*

Doctor Q: "I think we should have something like we have in things like chronic fatigue where you have a kind of multidisciplinary team which includes lifestyle experts. I think we should have such a pathway but that pathway has to be mindful that there may or may not be some endocrine pathology. If you have diabetes and you came to me with diabetes and you are still very tired and unwell, you know we'll do all the biochemical analysis and things but then I'll send you to my diabetes lifestyle group so there's a program which is targeted at patients with type two diabetes and within that program you have a Dietitian's inputs, you have an input from a diabetes specialist, you have input from an Exercise Physiologist or someone along that line um sometimes you even have an input from a kind of motivator or somebody with a psychological background. That program is very popular and it's very helpful for patients with diabetes It's not too farfetched to think of designing such a program for thyroid problems and that would help really where you have somebody who has the background of the endocrinology, the thyroid pharmacology and then you have somebody who's a lifestyle who's looking at the lifestyle aspect and both can work side by side. That might be a resource that would help"

Doctor R: "I often advise patients that going to see a Dietitian may help. Some GPs have access to that, others don't. We don't actually even in our clinic, which is large. We don't have access to a dedicated Dietitian, which I think would be useful, but there is no resource for that".

Doctor M: "we have some excellent Nurses in our department, and actually, they deliver a significant portion of both the hypothyroid and the autoimmune hyperthyroid workload now for the nurse-led clinics.

Doctor J: "clinical service here which is fortunately supported by the fact that there are a lot of Research Fellows working the clinics is that as a general role."

However, some participants felt that this was unlikely to happen due to the size of the problem and lack of available resources for the management of hypothyroidism.

Doctor N: "I'm not sure whether all the patients with hypothyroidism who don't feel well should go to multidisciplinary. I think there'll be too many"

Doctor N: "I don't think the NHS will be able to afford everyone who doesn't feel well, to go to multidisciplinary clinic, but I think for special group of patients, yes, it will be useful"

Doctor J: "I think Endocrinologists probably don't have the resource for that side of thing"

Participants felt that is essential to include patient-centred information to overcome issues of distrust and disregard and to provide information in line with patient-identified need and preference.

Doctor R: "We'd probably benefit from really good patient information centred around what can somebody do for themselves in terms of their own health um and I think it would be particularly powerful if it came from patient to patient groups rather than from doctors because I think sometimes it's was like distrust (…) I don't know (…) it's just kind of my feeling but you know if we had really good patient information that could signpost them to areas so to the kind of things I've just been talking about in terms of lifestyle changes, diet changes and managing stress and stress at home and about mindfulness maybe or other things and there could be psychological things happening that we could never even touch never mind try to treat in an outpatient setting"

Participants highlighted the valuable contribution of the evidence-based charitable sector, particularly the British thyroid Foundation and the Pituitary Foundation in providing trustworthy, evidence-based information.

Doctor F: "I emphasise the importance of that as a scientifically-approved organisation which has patients' interests at its heart and a very large patient base. I think using them instead of other sources of information is important and that people can often get a lot of support from that"

Doctor R: "I always tell them also that, not everything they find online is reliable and useful. There's a lot of fairly dangerous websites, what I consider dangerous websites on there, but I try to point them in the direction of recognised national bodies such as the BTF".

Doctor N: "I think the patient support groups are really important, and I think on the internet there is lots of things which are not true, so people who have stories how life changed just by taking one tablet of T3. I think patient support groups like BTF giving accurate and scientific information to the patient is really, really important"

Doctor J: "The Pituitary Foundation, we would very much say, there's very good quality information leaflets, materials that are available. They have been published and this though is a consequence of many experts and in the patients contributing to them you may find some of this information helpful."

4.4. Overarching theme 4: 'we can't do this alone'

This fourth theme includes participant-identified barriers to addressing the psychosocial needs of patients with hypothyroidism and supporting them to self-manage and highlights a need for change. This includes increases in funding and research, and a supportive environment which empowers clinicians to place patients at the centre of their care.

Subtheme 1: Funding

Participants highlighted that uncapped rises of generic medicines in the UK, including of LT3 is a primary barrier to clinician prescribing autonomy and patient treatment choice. Most participants reported that their local Clinical Commissioning Group has imposed a blanket ban on prescribing of T3 due to cost.

Doctor P: "I think the current pricing is outrageous uh it's absolutely outrageous"

Doctor G: "Also, another thing is the prohibitive cost of—especially in T3 and NDT in the UK is making it less available for the need patients nobody wants to prescribe it one, it's not in the guidelines, two the costs are so high."

Participants felt that this contributed to a stalemate situation where patients were denied trials of treatment options and this amplified anger and treatment dissatisfaction amongst patients.

Doctor B: "There's a point about the anger that's been generated around the cost and therefore, the lack of availability, and therefore the lack of experience, has made the situation about a hundred times worse than it needed to be because people feel angry and denied. That's an important amplifying factor in this problem."

Participants felt that the situation in the UK resulted in patients feeling forced to inappropriately self-manage by sourcing medication from outside of the UK to avoid feelings of helplessness and lack of control.

Doctor G: "prescribing habits are quite different in the United Kingdom compared to America, it's much more accepted to use NDT than here or in Canada it's much more accepted to use T3 or NDT than the UK. So It's all about accessibility, availability and it's physician experience as well"

Doctor D: "because some of the natural thyroid people buy from here, there and everywhere around the world"

Doctor E: “people going off to Greece stocking up on T3 pills. It’s about 2 euros a packet in Greece and about 300 quid in the UK.”

Participants felt that the lack of funding and availability perpetuates inequalities in health based on socio-economic status.

Doctor D: “So then patients have to self-fund tests so that they can get the parameters that will give us some measures.”

Doctor O: “I was going to say they're rich (…) he people we tend to see accessing those sorts of things are, I would say in general, are probably more high social class, more educated. Now, whether that's because they have the skills to go and look and find these things and work out ways of obtaining it, that's IT/healthcare savviness that other people don't, I'm not sure. I suspect it's probably is. We know that in all sorts of things, people who know their way around the system and I guess healthcare professionals, they're highest among those, but people who know their way around the system tend to get what they want a bit. That's probably true, not just the healthcare, that's quite true with lots of systems”

Participants felt that funding restrictions also contribute to scepticism and reluctance amongst some health practitioners towards the inclusion of the patient voice in research and creates safety concerns amongst the scientific community.

Doctor E: ”if a drug is hard to get and people have to jump through more and more hoops to get it. I do worry there's a placebo and a greater placebo effect produced as well. That makes me worry and it's something we'll have to all think about that that's one thing that you might see in the controlled trials that so far haven't shown a benefit. If there is a placebo effect and you make that drug had to get then you’re going to magnify that placebo effect. If people are getting drugs abroad or from less reputable sources, you've got a quality control issue there as well, the whole thing is a complete dog's dinner”

Subtheme 2: Research

In addition to addressing medication pricing and subsequent restrictions upon access to treatments, participants highlighted that investment in research is required to address scientific unknowns and to move the research conversation underpinning clinical guidelines forward. This was felt to be particularly important due to the issues surrounding the use of T3 and NDT casting shadow and doubt over patient self-management in this condition. Participants identified a need for definitive biomarkers for hypothyroidism, and trials to improve the safety and efficacy of treatments.

Doctor E: "Certainly I think there is evidence that TSH is not that brilliant of a marker for some patients"

Doctor I: "We certainly need prospective studies but at the moment, I think that the options for prescribing T3 are sub-adequate anyway because the half-life is so short"

Doctor P: "T3, I do prescribe. I always prescribe it with a heavy heart. I prescribe it with a heavy heart because I'm not perceiving that it's beneficial and because part of me believes that there is a theoretical possibility that that could actually be harmful to people in terms of uh the heart and bone health. I worry about prescribing it".

Doctor N: "I think obviously there is interest in long-acting T3 because some people think that the studies haven't benefited because T3 wasn't given in a correct physiological dose"

Doctor K: "I think the area where there is potentially an issue is subset patients who appear to benefit from combination treatment will need liothyronine where I think there isn't a consensus about how to manage those patients"

Some participants expressed positivity and hope that the need for research development was recognised in the new NICE guidelines and felt that with additional funding and investment progress to improve health and wellbeing outcomes for patients was in sight.

Doctor B: " I'm very keen that we, in the end, do the right trial to address that question because most of the studies that have been done at this point with T3 have not probably been done in the right way, and the results have been disappointing. When we are able to replace some closer to normal physiology, then we'll be able to sort out the wheat from the chaff a little bit"

Doctor B: " We're putting theories together as to why the previous trials have failed. I think there's some biological reasons why that could be the case. I'm led to understand that the NICE criteria will lead to potentially some funding for some more research in this area. I think that we can sort this out"

Doctor D: "I don't think that unless there's black and white evidence in medical literature, in other words, studies, I think general well-being and how people feel is too nebulous a concept for commissioners and prescribers to swallow"

Doctor G: "Quality of evidence is key to bringing the change"

Subtheme 3: Culture change

Participants highlighted a need for a whole systems approach to remove barriers to patient choice, and to support research progress. Participants described issues of concern to them including the blocking of treatments which may be crucial for some patients; and the withdrawal of medication from others to prove that without it, they become unwell. Participants felt concern at being stuck in the middle of being asked to put patients at the centre of their care by some parts of the health system directives, whilst being blocked and coerced by others.

Doctor D: "Sometimes, the NHS systems put barriers in place like GP practices or certain secondary care trusts where the biochemistry departments are situated won't do a T3 in a patient or a T4, they'll just do a TSH"

Doctor E: the one thing that's very common and what uh I can't work out why this has not been solved yet is the recent T3 crisis is difficult to take, we're seeing a lot of CCGs coming out with guidance to deny people T3 and that they're very inflexible and that makes me very angry and annoyed"

Doctor F: "Then I'm asked by the GP would I try to persuade the patient to stop these things. I think in those circumstances, obviously, it's wrong."

Doctor H:" I know x CCG is different ours do let us prescribe T3, but they need to see really clear pre-treatment, post-treatment. In fact, we're having to go back and look at our historic patients and actually take them off to prove that there's a definite benefit. They're not happy with just an outcome that could say they feel better."

Participants in this study identified a will and hope for change and progress towards a medical system which empowers and activates patients, supports their choices, and supports their wider psychosocial needs. However, Endocrinologists need support to raise patients with hypothyroidism up the political agenda and to receive funding, support and autonomy to place patients at the centre of their care.

Doctor C: " I think one of the issues around this is that thyroid disease or particularly hypothyroidism is profiled as relatively low it's not really as sexy as say cancer or diabetes. For commissioners of healthcare as well as deliverers of healthcare of thyroid disease common, is way, way down the priority list. You find that thyroxine is third most prescribed drug in the UK. It's staggering that people don't really take too much notice of it"

Doctor D: "It's a battleground, isn't it? Where in some respects the NHS pays lip service to the patient being the focus of concern to actually controlling what patients can and cannot have through financial means and guidelines. Clearly, there have to be some controls put in, but it's been, in my opinion fairly unsympathetic and created more hostility and more battlegrounds."

Doctor F: "Let me just emphasise again, I think this is an underfunded and neglected area. I call this an embarrassing secret of the NHS because it is the case"

Chapter 5: Discussion

This chapter discusses the findings of the analysis presented in Chapter 4 (‘Findings’) in relation to the aim and objectives identified in Chapter 1 (‘Aim, objectives, and rationale’) and to existing research that has explored similar areas. Implications of these findings to future research and practice are considered.

5.1. Endocrinologists views about the psychosocial and self-management support needs of patients living with hypothyroidism

In this study, participants highlighted that there are heterogeneous hypothyroid patient subgroups with diverse support needs. These include patients with: a new diagnosis; subclinical hypothyroidism (see 5.1. subtheme 2); symptoms of thyroid autoimmunity (including thyroid autoimmune overactivity, see section 5.3); survivors of thyroid cancer; patients with multi-morbidity and patients with persistent physical symptoms of unclear origin, or due to potential treatment inefficiency.

In Chapter 2.4. (‘The history of treatment for hypothyroidism’), patient heterogeneity was raised as one of the limitations of population-level trials of thyroid hormone replacement therapy (Dayan & Paniker, 2018). In the wider literature, heterogeneity of patient subgroups has also been attributed to modification of effects in varied treatment outcomes (e.g. Kent et al, 2010; Varadhan et al, 2013; Gil-Herrera et al, 2014). The current thesis recommends that future research and intervention should recognise and appropriately target different subgroups to improve treatment outcomes for patients with hypothyroidism.

Symptoms of Hashimoto’s disease: Two thirds of participants in this study reiterated previous research detailing a higher incidence of unresolved symptom burden and co-existing autoimmune diseases in patients with hypothyroidism resulting from autoimmune thyroid disease (Punzi & Betterle, 2004; Spirkova et al, 2015; Fallahi et al, 2016). A small number, however, did not think that autoimmunity plays a role in persistent malaise. This suggests that not all Endocrinologists provide education about the residual symptoms of thyroid autoimmunity. Those who did however, highlighted a lack of current treatments for Hashimoto’s disease other than LT4 therapy to restore thyroid hormone levels.

Autoimmune thyroid disorders are the most frequent organ-specific autoimmune diseases, involving about 5% of world population, Hashimoto’s thyroiditis is the most prevalent (Virili et al 2018). Autoimmunity research focuses on the breakdown in immunological self-tolerance and resulting inflammation in creating symptom burden (Figueroa-Vega et al, 2010: Wang et al, 2010; Ganesh et al, 2011). Studies with patients with autoimmune hypothyroidism (Hashimoto's disease) have reported presenting symptoms to include anxiety, negative mood, depression, dry skin, cold intolerance, puffy eyes, muscle cramps and fatigue, deep voice, constipation, slow thinking and poor memory (Van Zuren et al, 2013). However, little is known as to how much of the persistent symptom burden reported in literature regarding hypothyroidism is attributable to the lack of available treatment for Hashimoto's disease.

Research into the interaction of genotype with environmental triggers has led to interest in the role of the intestinal microbiota and dysbiosis in thyroid autoimmune disease onset (e.g. Mori et al, 2012; Virili et al, 2018), and an increased prevalence of celiac disease has been found in patients with autoimmune thyroiditis (Lerner et al, 2017). Subsequent interest is growing in research which explores whether dietary interventions and specific supplements (particularly selenium) might reduce antibody levels and alleviate resulting inflammation; and result in a decreased dosage of LT4 (e.g. Toulis et al, 2010; van Zuuren et al, 2013; Abbot et al, 2019; Wojas et al, 2019).

The findings suggest that condition-specific information and education may be required for people with Hashimoto's disease which may lie outside of the traditional Endocrinology remit and highlights a need for multi-disciplinary paradigms, for example incorporating Dieticians (see section 5.3., subtheme 3). Self-management support which teaches patients to access and use a range of informational resources has been developed for patients with rheumatic autoimmune diseases which are also characterised by systemic inflammation leading to target organ dysfunction (e.g. Dures et al, 2014a; Dures et al, 2014b; Dures et al, 2016). Future research may consider the feasibility of adopting these models of support for patients with autoimmune endocrinology conditions.

Thyroid cancer: Nearly half of participants in the current study mentioned the additional symptom burden of hypothyroid survivors of thyroid cancer. Whilst not a dominant focus of concern, the brief attention given to the subject here is interpreted as important as it reflects wider findings that this problem is a largely overlooked by clinicians but of importance to patients.

Thyroid cancer generally has a good prognosis. However studies (e,g, Applewhite et al, 2016) have identified that quality of life is similar to that in cancers with worse survival rates and that significant unmet informational and psychosocial support need exists in this patient group (e.g. Banach et al, 2013). Despite this, systematic reviews (Grogan et al, 2016; Parker et al, 2017) have found no studies to characterise morbidity or to tailor treatment strategies. One qualitative study with survivors of thyroid cancer (Smith, 2018) identified a lack of disease-specific information, isolation, body image concerns (scars), and concerns about the future (e.g. fertility) to be important amongst this patients treated for thyroid cancer. Concerns about stigmatisation resulting from semantics relating to the 'good disease prognosis'; feelings of disregard (i.e. delays in obtaining a diagnosis), and worries about subsequent hypothyroidism (lifelong reliance upon medication to achieve hormonal health) have also been reported as salient concerns (Easley et al, 2013; Smith, 2018).

In the present study, some participants felt that hypothyroid survivors of thyroid cancer may have condition-specific support needs, including a need for psychological support and for exercise intervention to address bone density loss following treatment (e.g. section 4.1; subtheme 1). The present study recommends that future investigation is needed to carry out a specific assessment to ascertain the psychosocial and self-management support needs in this patient group and whether these contribute to reports of treatment dissatisfaction reported in the literature. Multidisciplinary interventions (e.g. including by Exercise Physiologists – see section 5.3., subtheme 3) may also be appropriate for this patient group.

Patients for whom treatment may be ineffective: Participants in this study reiterated findings presented in Chapter 2.4. ('The history of treatment for hypothyroidism') that there may be a group of patients for whom treatment with standard LT4 therapy may be ineffective (e.g. Kalra & Khandelwal, 2011; Chaker et al, 2017; Wiersinga, 2014, Peterson et al, 2018, Dayan & Paniker 2018). They described investigations to rule out co-multimorbidity in the first instance (see section 5.2; Embedded is best). Following this, some but not all participants provide time limited therapeutic trials of LT3 or (a smaller number) of NDT thyroid hormone replacement treatment.

However, participants described paradoxical incentives and barriers to this approach including high patient demand for personalised or non-standard treatments on one hand and reductionism and scientific 'unknowns' on the other. This is reflected in the literature, through calls for increased attention to patient centred care (e.g. The Health Foundation, 2016) and patient activation (Alexander et al, 2012; Hibbard & Gilbert, 2014) set against directives to standardise testing and treatments (e.g. Daucourt et al, 2003; Pronovost, 2013; Toft, 2017; Jonklass et al, 2019; Taylor et al, 2019; see Chapter 2.4. The history of treatment for hypothyroidism' and Chapter 2.5 'Systematic review').

In the wider literature, factors at different conceptual levels (e.g. personal, social, financial, organisational) have been identified as barriers and enablers to clinicians' behaviour throughout the healthcare system (e.g. Michie et al, 2011). The current research identifies a mismatch between demands and barriers, leaving clinicians 'stuck between a rock and hard place' as described in Chapter 2.4. ('The history of treatment for hypothyroidism' e.g. Toft, 2017; National Voices 2017; Pulse Magazine, Sep. 2018; Dayan & Paniker 2018). Participants who offer trials of LT3, described doing so despite varied beliefs about efficacy and fear of personal responsibility for risk (see section 4.2. subtheme 2) but did so to address socio-political (universal) barriers (section 4.2. subtheme 3; section 4.4., subtheme 1) which they felt contribute to patients' sense of helplessness and subsequent anger and depression (Seligman 1972; Abramson, Seligman, & Teasdale, 1978).

If patients' symptoms did not resolve, participants expressed dissatisfaction associated with leaving these patients in a state of 'limbo' (see section 4.3, subtheme 3) without appropriate support and described a lack of service provision for these patients, except referral back to the GP. Participants in the current study described managing difficult and emotional interactions with patients in response to perceived denial of treatment (section 4.2. subtheme 3), or when treatments failed to resolve symptoms.

Recommendations have been made in the literature for new models of working to address quality of life in patients who are dissatisfied with thyroid treatment (Hoermann et al, 2017; Toft 2017; Midgley et al, 2019) and to improve healthcare for patients with persistent symptoms (e.g. Joint Commissioning Panel for Mental Health, 2017). Psychosocial interventions based on Seligman's (2011) model of 'learned optimism' have been found to promote positive social and psychological appraisals and wellbeing and to restore personal control and resilience amongst patients living with cancer (e.g. Zollman et al 2017; Seiler & Jenewein, 2019) and may support Endocrinologists to address the psychosocial needs of this patient group whilst maintaining validation of patients' illness experiences (see section 5.2., subtheme 3). Recommendations have been also been made that all healthcare professionals are provided with training to develop the skills to work effectively with patients with persistent or unexplained medical symptoms (e.g. 'Joint Commissioning Panel for Mental Health, 2017) and may address the negative impacts upon their own job satisfaction described by some participants in this study (section 5.3. subtheme 2).

Participants reiterated reports in the literature that the heterogenous patient subgroups described above face a range of issues which effect their quality of life including; lethargy and fatigue (Van de ven et al, 2012), poor control over weight (Kelderman-Bolk et al, 2015); anxiety and depression (e.g. Alsaffar et al, 2016); poor health related quality of life (e.g. Watt et al, 2006), impairment in psychological wellbeing (Saravanan et al, 2006; Saravanan et al, 2002; Paniker et al, 2009; Wekking et al, 2005; In Taylor et al 2019). poor general mental health (e.g. Saravanan et al, 2002).

Participants recommended that support is needed from the point of diagnosis, particularly for newly diagnosed patients and those with subclinical hypothyroidism (for whom findings of slightly abnormal biochemistry may or may not be a clear indication of disease). An online leaflet (NHS UK, 2018) supports this idea. The information tells patients that early diagnosis is essential, stating: “A hypothyroid state can change the way the body processes fat. This can cause high cholesterol and atherosclerosis (clogging of the arteries), which can potentially lead to serious heart-related problems, such as angina and a heart attack”. However, the information sheet provides no follow up to support patients with the impact of this information. One study (Smith et al, 2018) draws attention to the emotional impact upon patients of learning that they require lifelong thyroid hormone replacement medication to maintain their hormonal health but emphasises a lack of support in this area.

Participants highlighted that limited condition-management information exists, and that supportive information is not routinely offered in primary care. One patient information booklet (American Thyroid Association, 2013; p.22) highlights that patients may experience the issues highlighted by doctors in this study including; feelings of disregard during seeking a diagnosis, an emotional response to diagnosis, need for expectation management, and feelings regarding the lack of cure, lifelong need for management and scientific unknowns. The booklet makes recommendations for lifelong commitment to treatment, adherence and good partnership working with doctors. However, the current study highlights that early support and a collaborative approach is currently lacking for UK patients with hypothyroidism in primary care. In response to the lack of suitable information for patients in the UK, the author of this thesis was invited to collaborate with the British Thyroid Foundation in 2020 to develop and publish an information leaflet for patients about ‘Coping with the psychosocial impact of hypothyroidism’ (BTF, Jackson, & Griffiths; 2020).

The benefits of early support perceived by participants in this study reflect calls to identify new models of working in primary care (NHS England 2016; Baird et al, 2016). These include delivering interventions at the point of prescribing and providing regular reviews to optimise the therapeutic outcomes of medications; to prevent waste and subsequent the cost to the NHS (Hazell & Robson, 2015). Support for this exists in previous research (Dew et al, 2018) which found suboptimal treatment of hypothyroidism in primary care despite clinician attitudes that the condition is straightforward to treat (Chapter 2.6. Examining clinicians’ attitudes, beliefs and intentions towards self-management and psychosocial care). Participants in the present study have highlighted a lack of review and suboptimal management in primary care as a primary reason for patient reports of treatment dissatisfaction, poor physical and psychological outcomes, risk of non-adherence (e.g.

seeking or self-sourcing alternative thyroid hormone replacement therapies) and for increased demand upon secondary care.

Despite identifying the diverse support needs of patients with hypothyroidism, participants varied in attitudes and perceived confidence and ability to explore psychosocial and self-management issues with patients in their own practice. A small number of clinicians reported feeling comfortable and happy to probe patients who they thought might be struggling emotionally whilst a minority felt that addressing psychosocial issues lay outside of the clinical remit.

This reiterates findings in the wider literature that doctors vary in will and confidence to incorporate non-medical models of care. For example, in a survey of 304 doctors and 1,006 patients in the US, Jonas et al (2019) reported that only 53% of doctors believed their patients would be interested in discussing self-care, compared to 72% of patients. Dures et al (2016) found that only a quarter of rheumatology patients reported being asked about social and emotional issues by their clinician.

In the current research, most participants felt that they primarily lacked time, then skill and support to explore patients' psychosocial and self-management needs. Similarly Jonas et al (2019) reported that 78% of physicians reported a lack of time as the top reason they did not discuss self-care with their patients, and also as one of the reasons physicians say they did not personally practice their desired amount of their own self-care.

5.2. Endocrinologists' experiences of providing psychosocial and self-management support within their own practice and referring patients with hypothyroidism for psychosocial and self-management support

Participants described the roles they held in supporting patients with persistent symptoms. These included: building a doctor-patient relationship based on trust; listening; validating patients experiences; reducing the perceived battleground between patients and the healthcare system; ruling out co-morbidity; optimising therapeutic effects of treatment and increasing adherence; providing quality information and education; provision of therapeutic trials (but not all clinicians); management of expectations through goal setting and action planning; and reiteration of healthful behaviours.

Participants described listening to patients' experiences of their symptoms and trying to understand the beliefs that shape patients' perceptions of the threat to their health. In response, participants described addressing inaccurate beliefs and ideas which they felt were often formed by information online (see section 4.2. 'Professional identity'). Participants described carrying out extensive tests to rule out biological co-morbidities and educating patients to form alternative explanations for their symptoms (reinterpreting physiologic symptoms; Lorig & Holman, 2003).

The application of theory may support Endocrinologists to work collaboratively by providing frameworks to explore and address their patients' beliefs about hypothyroidism and to tailor education to fit individual representations (Baumann, et al, 1989; Petrie et al, 2003). For example, in the 'Common-sense model of self-regulation' (Leventhal et al, 2003) patients are viewed as independent problem-solvers who actively process health information to create understandings that guide health-related decisions and behaviour. Training for Endocrinologists in the theory and skills of self-management may help them to address the accuracy and coherence of patients' lay beliefs (Moss-Morris et al, 2002; Leventhal et al, 2003); to improve their self-efficacy and understand their condition; to avoid ineffective and potentially unsafe self-management behaviours (including self-sourcing medications) and to improve their health outcomes (Breland et al, 2020).

Whilst participants were generally supportive of patients making decisions to utilise wider strategies and complementary approaches to improve their wellbeing, they described challenges to their professional identity as the biological expert when patients adopted an active health consumer role. Specifically, some participants described their struggle to devolve power to patients when they felt that 'scientific unknowns' presented potential risks to patients' health; when they felt that patients misinterpreted clinical guidelines, and when patients self-sourced non-standard hormone replacement therapies in response to dissatisfaction with reductionist treatment approaches. This reflects wider findings that clinicians' struggle to endorse patient activation when they perceive that associated activity contradicts clinical advice (e.g. NHS England, 2015). Some described being caught in a 'battleground' between paradigms and felt that some patients presented with fixed a fixed agenda (i.e. to obtain LT3) and an 'us and them' approach to the consultation, fuelled in part by engagement with online patient groups (section 4.2, subtheme 3: 'Difficulty shifting the focus').

This phenomenon is argued to reside within an emerging paradigm clash between modern subjectivist treatment philosophies and traditional positivist approaches. Newer treatment philosophies challenge the concept of professionalism in medicine (e.g. Madden, 2012) through increased patient autonomy and treatment responsibility. In contrast, the traditional medical model holds a core belief that patients require guidance on medical treatments and that knowledge and experience supersede the need for a patient-centred approach (e.g. Rogers et al, 2005).

The impact upon the doctor-patient relationship resulting from the clash between activation and standardisation is described as a contentious issue throughout modern healthcare (e.g. Madden, 2012). Within endocrinology, for example, Snow et al (2011) found that patient education to increase condition-specific knowledge in patients with Type 1 diabetes led to fraught interactions within the healthcare system. This stemmed from patient perceptions that restricting access to medications perpetuates power imbalances which impede their ability to self-manage. Concurrently, healthcare professionals felt unsure of their patients' actions and uncomfortable to trust their expertise.

Incorporating theoretical approaches, such as 'Social Identity Theory' (Tajfel, & Turner, 1979) may provide a useful framework through which to further examine conflicts and challenges to participants and patients' identities described here. Potentially, a reluctance to incorporate patient-centred support may be viewed as socially identifying with the 'profession' and against the 'discrediting' of science and clinical guidelines. Similarly, identifying with polarised patient groups which label Endocrinologists (as knowledgeable or uncaring) may protect patients against perceived connotations of being left without answers or labelled with unhelpful terminology including 'medically unexplained symptoms', the impact of which is described by participants in this study and elsewhere (e.g. Marks & Hunter, 2015; Joint Commissioning Panel for Mental Health, 2017). Incorporating identity theory frameworks into future research and training may provide an opportunity for clinicians to identify and challenge assumptions about the nature of professional identity within the changing role of the medical profession (e.g. Burford, 2012).

Participants felt that patients were less resistant to having their ideas and treatment beliefs challenged when clinicians 'kept the door open' to biological explanations for their symptoms. However, attempts to shift from a biological focus were often met with anger and upset. This was particularly so when participants tried to discuss mental health (e.g. depression) or psychosocial (e.g. work stress) issues which may impact upon symptom development or progression; or when they tried to refer patients for supportive care (e.g. to a Dietician).

Some participants noted that patients with symptoms of hypothyroidism have traditionally experienced dismissal from other health professionals, contributing to 'us and them' polarisation. This is reiterated in a patient booklet (American Thyroid Association, 2013; p.22) which recognises that many people are diagnosed with hypothyroidism after feeling sick for years or believing or being told their symptoms are "all in your head," "just stress," or "a normal part of aging".

Participants therefore felt it important to focus on biological causes of persistent symptoms, and worried that a shift in focus away from thyroid biology would be interpreted by patients as stigmatisation, invalidation of their illness experience, or that the clinician had somehow failed. Participants also resisted ‘moralisation’ (e.g. Brown, 2018) through questioning patients’ health behaviours, and highlighted that many patients were well read and activated (although vulnerable to misinformation online), and had already tried many approaches to alleviate their symptoms. Often, they described feeling stuck to shift the focus of the consultation towards non-medical issues in a way which would be acceptable and useful to patients. These findings support wider findings from a study using the ‘Theory of Planned Behaviour’ (Ajzen, 1991; 2002) that clinicians are less likely to implement self-management if they did not believe that ‘important others’ (patients and senior figures) are on-board with the model of care (Anderson & Ozakinci, 2019).

In the literature, overlap can be found with other conditions. For example, debate and anger has grown following a clinical trial which concluded that adding cognitive behavioural therapy and graded exercise therapy to specialist medical care improved recovery for people with ME/CFS. Debates focused on the terminology used in the trial dispute that ‘recovery’ can be achieved through non-medical treatments and highlight the implications of these finding upon the organic classification of the disease (e.g. Torjesen; 2018). One participant in this study emphasised that any potential psychosocial or self-management interventions (section 4.3. Subtheme 3: ‘Assets and strengths’) should be mindful of endocrine pathology. This is consistent with recommendations that psychosocial interventions should address the ways in which illness has woven itself into the daily texture of the patient’s existence rather than to search for alternative causes of symptoms ‘within the mind’ (Deary, 2017).

5.3: Perceived facilitators to the implementation of psychosocial and self-management models of care

Around half of participants in this study emphasised the need to incorporate patients as respected partners in their care; to solve problems with them not for them and to avoid reducing them to passive recipients of care. This approach is echoed in the NHS ‘House of Care’ model for long term conditions which takes into account the expertise and resources of the people with LTCs and their communities (NHS England, 2019a). Participants who did not express these views tended to perceive hypothyroidism as an acute illness, with symptoms which should resolve with standard treatment, and were less likely to engage patients within a co-creative and participative approach (e.g. Hardyman et al, 2015; Graffigna & Barello, 2018). However, these participants reported lower levels of satisfaction in their interactions with this patient group.

In Chapter 2.5 (‘Systematic review’) one-way interventions to provide information to patients reported no treatment effect upon health outcomes, for example in increasing adherence to LT4 (Crilly & Esmail, 2005). This was reiterated by one participant in this study who highlighted that more than information-giving is required, and that it is important to engage patients to understand what is important to them (their fears, needs and preferences).

Recommendations in the wider literature have been made to value the role of patients as partners and problem solvers particularly when patient illness or treatment expectations are mismatched with those of the provider (Young & Flower, 2002), as participants in this study identified in section 5.1 (‘Subtheme 2: ‘Diverse support needs’). Involving patients in their care is an opportunity to narrow polarisation between patients and the medical profession (Young & Flower, 2002) identified in section 5.2. (Subtheme 3: ‘Difficulty shifting the focus’) and has been identified as a key strategy to reduce feelings of disregard amongst patients, particularly those with persistent or medically unexplained symptoms (Houwen et al, 2017).

In primary care however, Dew et al (2018) found that only one GP reported treating a patient with hypothyroidism according to a collaborative and autonomous patient-doctor agreement. In the present study over half of participants reported being more comfortable than GPs to collaborate with patients. However, the conversation around collaboration in this study focused almost exclusively on whether or not to support non-standard hormone replacement therapy.

A number of participants raised the issue that using patient reported outcomes measures (PROMS) which are informed by the values, attitudes, and perceptions of patients (Dowling et al, 2016) may be a way to improve the patient voice in collecting evidence relating to hypothyroidism. Specifically, some described using the ‘Thyroid-Related Quality of Life Measure’ (ThyPRO) (Watt et al, 2014) to examine quality of life improvements in patients undergoing clinical treatments in their own practice, and reported increasing use of this by Clinical Commissioning Groups (CCGs).

Some participants were sceptical however about the potential for bias within PROMS, as they were about anecdotal evidence from patients, which indicates that not all Endocrinologists trust in a partnership approach to the management of hypothyroidism. More work is required therefore to build collaborative bridges between patients with hypothyroidism and their care providers. Training for clinicians in the theory and skills of self-management may include them in the research conversation about issues of reliability and validity in the use of PROMS and may decrease scepticism. For example, research has found support for the clinical reliability and test-re-test validity of the Thy-PRO for use in clinical settings (e.g. Watt et al, 2010).

All participants felt that involving patients with hypothyroidism in their own care from the point of diagnosis may help to manage patient expectations (see section 5.1. Subtheme 2: 'Diverse support needs'), improve coping skills, and stem the flow of dissatisfied patients backwards and forwards between primary and secondary care. In the wider literature the term 'revolving door' has been used to describe conditions where patients may spend many years seeking help, often getting stuck seeing a variety of specialists (Blyth et al, 2004; Clare et al, 2013). Dew et al (2017) recommended that educating patients in primary care regarding the consequences of inadequate thyroid hormone replacement may improve long term treatment outcomes for patients with hypothyroidism. Participants in the present study felt that this is important to address to remove patients with hypothyroidism from the revolving door.

Recommendations have been made for access to patient-centred care that is responsive to individual patient preferences, needs and values at the primary-secondary care interface (e.g. Sampson et al, 2015) and to engage with patient groups, and the voluntary and community sectors to prevent patients becoming caught in a 'no-mans land' between primary and secondary care (NHS England 2017).

Recommendations have specifically been made for an increased focus on asset-based models which emphasise shared decision making for patients with subclinical hypothyroidism in primary care (Cheong, 2019; Jenkins, 2019; Sanday, 2019; Forsyth, 2019; Bekkering et al 2019b). Beyond hypothyroidism, it has been found that engaging patients in primary care as 'assets' in the planning of care is an effective strategy in the management and control of symptoms and secondary prevention for patients with chronic health conditions (Dineen-Griffin et al, 2019).

Assets can be described as the collective resources which individuals and communities have at their disposal (McLean, 2012). Asset-based approaches begin with identifying a community's capacities and encouraging it to help itself (Noble-Jones et al, 2019). Multi-professional staff and the charitable sector are assets that patients might use alongside their own assets to promote capacity, connectedness and social capital (NHS Health Scotland, 2011; Noble-Jones et al, 2019). To enable this approach requires health professionals to collaborate, alongside the transformation of the health service workforce to work differently (Adkins et al, 2017; NHS Scotland, 2018; Health Education England, 2017).

Participants identified the untapped value of asset-based collaboration with multidisciplinary colleagues (Endocrine Nurses, Health Psychologists, Dieticians, embedded Researchers, Exercise Physiologists and Pharmacists) and the evidence-based charitable sector to address gaps for patients with hypothyroidism in primary and secondary care. Collaboration is defined as an interactive process that enables people with diverse experience to generate creative solutions to mutually defined problems to develop enhanced outcomes (Idol et al, 1995). According to systems theory, this is key to improving performance in the healthcare system (Walshe & Rundall, 2001; Glanz et al, 2008).

Participants felt that multidisciplinary self-management approaches could help to meet the diverse needs of people living with hypothyroidism. Participants talked about approaches used in the care of patients with type 2 diabetes which may be adaptable. However, some participants noted that the NHS was unlikely to fund such provision.

Multidisciplinary diabetes care teams utilise collaboration between specialists as required, from the point of diagnosis and provide care across the primary-secondary care interface which recognises the divergent needs of people living with diabetes (Diabetes UK, 2010). The effects of multi-disciplinary self-management support within this area of endocrinology are recognised worldwide (e.g. Hreha & Noce, 2018; Tan et al, 2019).

In the case of thyroid disease, multidisciplinary approaches are included within the National Cancer Plan for patients with thyroid cancer. They consist of Oncologists, Radiologists, Pathologists and Clinical Nurse Specialists (Mallik, 2006; Hewett, 2007) with support from the evidence-based charitable sector (e.g. The Butterfly Thyroid Cancer Trust). However, calls have been made in the literature to improve current service provision through incorporating knowledge translation and psychosocial support (e.g. Hyun et al, 2016).

Multidisciplinary approaches for patients with thyroid eye disease (TED) have also been recommended (Perros et al, 2015) to improve care for people with TED. Endocrine teams are required to identify a specialist multidisciplinary thyroid eye clinic in their region and refer all patients with moderate or severe TED affecting the patients' quality of life to this service (Draman et al 2017). Research from a health psychology paradigm however (Wickwar et al, 2015) has highlighted that development of psychosocial interventions targeting appearance-related cognitive processes are yet to be funded and developed to enhance the quality of life outcomes for patients with TED undergoing orbital decompression surgery. In 2017, the author of this thesis was invited to present at a TEAMeD patient information day, and to provide multidisciplinary team training as part of the 'teaching and training' requirements for the Professional Doctorate in Health Psychology.

Participants in this thesis highlighted a need for multidisciplinary approaches for patients with hypothyroidism but felt that funding in this area was unlikely. This heterogeneous patient group includes survivors of thyroid cancer, and patients who have been treated for TED. It also includes (as discussed in 5.1: subtheme 1) patients with high levels of multimorbidity for whom multidisciplinary approaches have been recommended in the literature. For example, thyroid disease has been found to be a common comorbidity in patients with heart failure and multimorbidity (Stewart et al, 2016). Participants also highlighted a lack of training and referral services to support communication with patients for whom the cause of symptoms could not yet be identified. Calls for health professional training and for multi-disciplinary service provision for patients with persistent symptoms have also been made (e.g. 'Joint Commissioning Panel for Mental Health, 2017).

This thesis therefore recommends that there is a significant rationale to fund research to develop and evaluate multi professional self-management interventions for people with hypothyroidism but as of yet, no such service exists, despite thyroxine being the third most prevalently prescribed drug in the UK (NHS Digital, 2017).

Participants highlighted that important expertise could be provided by Endocrine Nurses, Health Psychologists, Dieticians, Exercise Physiologists, and embedded Researchers to improve outcomes for patients with hypothyroidism. Recommendations have also been made in the literature for pharmacists to play a key role in delivering medical and behavioural modification interventions (e.g. Jonklaas & Kane, 2017), although it has been found that Pharmacists may play a more substantive role if they had access to the medical notes of patients to support the optimisation of thyroid treatment outcomes in primary care (Dew et al, 2018).

Participants also highlighted the essential role of the British Thyroid Foundation and the Pituitary Foundation in providing trustworthy evidence-based information and support for patients (see section 5.5 'Endocrinologists' views and experiences of referring patients for psychosocial and self-management support') and for helping to combat inaccurate or misleading online messaging.

Research has found that when patients perceive a lack of condition-specific informational or other support they seek identification with others who have experienced the same condition to provide shared understanding, positive role models and to obtain information about coping (Smith et al, 2018). This is the case for survivors of thyroid cancer (e.g. Easley et al, 2013; Smith et al, 2018) and has been identified by participants in this study for patients with hypothyroidism who commonly experience loss of social support, including loss of work and problematic relationships with others

(Thilvum et al, 2014, Brandt et al, 2015; Naxo et al, 2015, see 2.2. 'Complexity and persistent symptoms').

However, when individuals without the right knowledge or experience support others and facilitate peer interventions, it has been found to exacerbate the original problems through the provision of unproven or incorrect advice (e.g. Department for Education, 2017). Participants in the present study, however have highlighted the positive value of support from expert peers which is not available from friends and family (Matthews 2000; Coyne & Borbasi 2007; Clarke et al, 2011) and support recommendations for commissioning which views evidence-based peer support as essential to the future of the NHS, (including NHS England's 'Five Year Forward View' in 2014; and a joint NESTA and National Voices review, 2015).

Self-management support for patients with hypothyroidism should therefore incorporate and support the charitable sector to provide key elements of self-management support. These may include resource utilisation, modelling and self-tailoring (Lorig & Holman, 2003) to increase patients' knowledge and understanding of their condition and the consequences of suboptimal treatment or over-replacement of thyroid hormones (Brown et al, 2005; Dew et al, 2017) and to provide education on issues relating to the impact of the disease and treatment on quality of life (Grogan et al, 2016; Banach et al, 2013).

5.4: Perceived barriers to the implementation of psychosocial and self-management models of care

In Chapter 2.7. ('Defining Psychosocial and self-management support') it was highlighted that investment into the 'Personalised Care model' including self-management support, is included the 'NHS Long Term Plan' (Alderwick & Dixon, 2019). Programmes which activate and empower patients have been associated with a reduction in health inequalities, delivery of improved outcomes, better quality care and lower costs (e.g. Lorig & Holman; 2003; Hibbard & Gilbert 2014; NHS Education Scotland 2014; Self-Management UK, 2017; Anderson & Ozaninci, 2019). Within this model, self-management training can help health care professionals to work with 'what matters' to people, based on their individual assets, needs and preferences, as well as to take account inequalities and accessibility barriers (Dures et al, 2014.2; NHS England, 2019a).

Paradoxically (see section 5.1. Subtheme 1), participants in this study identified uncapped rises of the cost of LT3 and restrictive practices from CCGs as limiting patient treatment choice and clinician prescribing autonomy and promoting reductionist, directive approaches. They described restrictions to NHS services based on cost as creating health inequalities (access to private appointments and self-sourced treatments become based on socioeconomic status and internet-savviness) and research bias (reporting in the THY-Pro). Some participants felt that standardisation of treatments diminishes clinician experience (of using non-standard therapies) and undermines patient safety (patients source medication from abroad and self-medicate without support from clinicians). This reflects wider criticisms and concerns about rising costs of and the uncertain future of generic medications in the UK (House of Commons, 2018), which effect a wider range of patients with chronic illnesses beyond those with hypothyroidism.

Call are therefore made within this research that echo others (e.g. Ewbank et al, 2018) to address the rising costs of medicines in the UK, and to provide resources to include patients with hypothyroidism within the 'House of Care' in which clinicians are supported by organisational and clinical processes and commissioning to put patients at the centre of care (NHS England, 2019a; see section 5.3: subtheme 1).

Participants expressed hope resulting from new NICE recommendations (2019) for trials to examine LT4 – LT3 combination therapy for people with persistent hypothyroidism symptoms, and in the effectiveness of LT4 for people under 65 with symptomatic subclinical hypothyroidism. The present study highlights the importance of these investigations and calls upon the NIHR for funding to address 'scientific unknowns' which perpetuate ambiguity in the management of hypothyroidism and present barriers (particularly clinician attitudinal and behavioural barriers) to the development and endorsement of psychosocial and self-management models of care.

In addition, participants have identified a need for investment in research to trial a new long-lasting LT3 preparation to address current safety concerns relating to patient treatment choice and to develop quality biomarkers to support diagnosis. A subgroup of participants also highlighted the need to embed a wider range of wellbeing and patient-reported measures into the research conversation to capture a wider range of wellbeing outcomes and incorporate the patient voice (section 4.3; subtheme 1).

This thesis recommends that research should move beyond limited informational interventions which reduce patients to passive recipients of care (see Chapter 2.5. 'Systematic review') to incorporate self-management approaches used in other treatment areas which orientate patients as partners in the care process, for example in; arthritis (Lorig, 1982; Lorig & Holman 2003; McBain et al, 2018), chronic pain (Traegar, 2014), CFS/ME (Castell et al, 2011; Núñez, 2011), rheumatology (Dures et al 2016), and cancer (Polley et al, 2016).

Multidisciplinary research is also required to improve the weak quality of physical interventions (also reported in Chapter 2.5: ‘Systematic review’) to support physical recovery from hypothyroidism (Singh, 2011; Cotovic et al, 2012; Garces-Ateaga et al, 2013) within the research literature. Nutritional and dietary self-management interventions (e.g. Wang et al, 2018; NICE, 2019; e.g. Abbot et al, 2019) should be recognised as a growing area of interest for patients, particularly for the management of autoimmune thyroid disease, to potentially reduce need for surgical thyroidectomy, and for survivors of thyroid cancer.

However, participants’ accounts and interpretations in this section recommend that caution must be given to ensure that future interventions are developed as complimentary rather than primary therapies and that their delivery must remain mindful of endocrine pathology. Elsewhere it has been emphasised that asset-based approaches are not a replacement for investment in service improvement, or for addressing the structural causes of health inequalities (Glasgow Centre for Population Health, 2012; Noble-Jones et al, 2019). Participants in this study highlighted that work is required to engage patients in the process to determine what issues are of importance for them. This may be conducted through the charitable sector to address issues of patient distrust in the healthcare system raised in this study.

Most participants in this research identified as motivated to adopt personalised models of care and a self-management paradigm where the needs of the patient are viewed as a starting point for exploration and development of new solutions (Reid et al 2005). However, numerous extrinsic barriers between ideals and practice were identified which have reflected descriptions of Endocrinologists as ‘stuck between a rock and a hard place’ regarding the treatment of patients with hypothyroidism (see section 5.1; subtheme 1).

The challenge of integrating clinical care that is consistent with scientific evidence yet gives room to patients’ personal contexts and emotions and empowers them to manage their health (see section 4.2. subtheme 2) has similarly resulted in findings of dissonance through the literature (e.g. Butalid et al, 2014). This highlights the importance of addressing social norms and control factors which mediate health professionals’ intentions to implement self-management models of care (Dures et al, 2014.1; Ernst et al, 2018; Anderson & Ozakinci, 2019). For example, clinicians reportedly cite a lack of referral options as one of the top three barriers to acceptance and use of diabetes self-management support (Mulvaney, 2009; Peyrot et al 2009).

Restrictions upon autonomy and competence were identified by participants in this study, and the subsequent impact upon relationships with patients. Some argue this highlights the potential threat of disruption posed by asset-based models of working to the status quo within modern medicine and public health (e.g. Hopkins & Rippon, 2015). Specialist and reductive approaches are cautious and risk averse and directives to adopt new ways of working may be met with a lack of support from different healthcare paradigms, leaving clinicians stuck in the middle stuck and in fear of risk and blame (Telegraph, 2014).

Theoretical frameworks such as Self-determination theory (SDT) (Ryan & Deci, 2000; Deci & Ryan, 2012; Ryan & Deci 2017) identify that such a mismatch in intrinsic and extrinsic sources of motivation may result in a detrimental impact on clinician wellness. A small number of participants described their experiences of supporting patients with hypothyroidism in terms including 'trepidation', 'dissatisfying' and 'heartsink' suggesting a degree of helplessness and burnout in the lack of perceived progress. Burnout has been defined as a state of exhaustion and cynicism about ones' capacity to make a difference (Maslach et al, 1996; Schaufeli et al, 2009) resulting in apathy, fatigue, anxiety, low job satisfaction and withdrawal behaviour; negative attitudes towards self and others and belief ones work related gaols can and have not been achieved (Bakker & Demerouti, 2007; Adebayo, 2011).

Other participants described positivity and hope for the future. These clinicians were more likely to report 'task identity' in offering therapeutic trials of non-standard medications to patients, engagement in research and guideline development, and were more likely to be supported by researchers and specialist Endocrine Nurses within their thyroid clinics. Task identity is described as job characteristics that stimulate personal growth and enable employees to maximise use of their talent and ability (Hackman et al, 1975) protecting healthcare staff against diminished motivation and burnout (Bajwa, et al , 2010; Adebayo, 2011). The findings of this research highlight the importance of addressing the mismatch and between clinicians' motivations and professional values and the realities of practice (Agarwal et al, 2020) and providing them with the necessary resources to move forward.

British Medical Association (BMA, 2020) suggests that change is required to improve care for patients but also for the working lives and wellbeing of doctors in the NHS, including the promotion of learning and time for reflective practice. The review carried out in Chapter 2.5 ('Systematic review') recommends that this includes training in the theory and skills of self-management support. However, system change is also required to address the funding deficit, to empower doctors and NHS staff to work together across traditional organisational divides and to create a culture that promotes innovation and development that is not rooted in blame (BMA 2020). The findings of this thesis therefore reiterate that integration of psychosocial and self-management support within health care delivery requires a whole system approach, not just negotiation between patients and healthcare providers (Weckowicz 1989; Rogers et al, 2005; Alexander et al, 2012).

5.5. Strengths and limitations

Strengths

The strength of this research stems from the commitment to quality and rigour embedded at all stages, and through incorporation of best practice frameworks for the design, conduct and analysis of qualitative research (e.g. Meyrick, 2006; Yardley, 2000; Braun & Clarke, 2006). These processes are described in section 3.2. 'Quality issues in qualitative research'.

Methodological limitations

This research has generated accounts and experiential descriptions (Braun & Clarke, 2006, p. 174) of the views and experiences of participant Endocrinologists. It did not examine the latent content of data which would have also been possible using reflexive thematic analysis (Braun & Clarke, 2006) to interrogate the assumptions, ideas and discourses that may underlie and shape the spoken narratives of individual professional attitudes (e.g. Evans & Lewis, 2018).

Future qualitative research using different methodologies may add depth of understanding to this subject area. For example, Madden (2012) used a discursive approach to explore the challenges of the shifting modern healthcare terrain upon the identities of general practitioners and patients, and upon the shifting practitioner-patient relationship. Discourse analysis was used to explore the paradoxes and paradigm clashes between treatment philosophies, issues of professionalism and the standardisation of treatments, power relationships and debates around dominance and subordination.

However, the findings from the current research also identify participants' broad accounts of the medical paradigm and the perceived challenges to role and identity of incorporating components of psychosocial and self-management support. These issues were first identified in Chapter 3.1. ('Rationale for qualitative approach: Development of researcher's epistemological and theoretical stance') through the perceived level of importance assigned to the research topic by different PPI contributors, and the different levels to which they felt that this research was relevant to the clinical remit. It was identified again in the same section when one PPI contributor highlighted that Endocrinologists were likely to struggle with healthcare semantics from a Health psychology paradigm.

These differences in 'knowledge' between the Health Psychology paradigm and medical participants, were used to shape the selection of the current research ontology and epistemology which has aimed to conduct a broad exploration of the accounts of Endocrinologists' at a level which targets and values the partially 'knowable' with a view to applying this knowledge to make a difference or bring about change.

Sampling limitations and risk of bias

The use of a snowball sampling method sought to improve recruitment of Endocrinologists who may be considered a 'hard to reach' group based on their employment status and time constraints. During the planning stages of this research, PPI contributors were included to establish the quality and trustworthiness of the research, with reference to sensitivity to context, commitment and rigour, transparency and coherence. However, as highlighted in section 3.1. ('Rationale for qualitative approach: Development of researcher's epistemological and theoretical stance') one Endocrinologist rejected the research importance of persistent symptoms in hypothyroidism and withdrew from the project. Whilst this view was unsupported by two other Endocrinologists, this experience shaped the recruitment strategy which then attempted to raise the profile of and recruitment to the study by asking Endocrinologists (rather than the researcher, a doctoral student) to invite other Endocrinologists who may be agreeable to the research cause to participate.

This method was successful at increasing participation and the appropriate sample size for a UK professional doctorate project using thematic analysis (6-15 interviews; Braun & Clarke 2013, adapted in Terry et al, 2017) was exceeded. However, this sampling technique may have biased recruitment towards inclusion of people with similar interests, particularly those who professionally identify through developing research and practice in this topic area (e.g. Parker et al, 2019). To minimise this, participants were asked to consider colleagues who both supported and opposed their views, based on knowledge of polarisation identified through extensive engagement with the literature. The resulting data does demonstrate differences in accounts regarding practice (e.g. a wider range of views regarding LT3 and NDT hormone replacement treatments) but this may still not be representative of Endocrinologists as a whole. The aim of this research, however was not to provide generalisable or representative findings, which may be valued within positive research; rather to give novel accounts and insights from Endocrinologists with a particular interest and expertise in the management of complex hypothyroidism, regarding non-medical models of support for this patient group.

Further research may address these limitations through adoption a of pragmatist approach to take what is presented here and test out themes on a larger scale, to look for wider patterns of agreement and divergence in the Endocrinologist population (e.g. through a mixed methods survey). However, caution in this approach is advised as Endocrinologists in this research were not fluent in language relating to the theory and skills underpinning the facilitation of self-management and this approach may require the provision of appropriate definitions or may be suitable to evaluate attitudes post-skills based training.

Interpretive and reflexive considerations

Health service research often focuses on generation of theory or to test the use of existing models in novel situations. For example (Dew et al, 2018) using grounded theory to explore data and generate theory regarding patients' and clinicians' attitudes towards the medical management of hypothyroidism in primary care.

The aim of this research however was to provide a starting point; to provide experiential accounts of the views and experiences of participants and of the social and political contexts in which they are situated. However, the findings from this research were interpreted in this discussion section by a trainee Health Psychologist with extensive engagement with the background literature regarding the medical treatment of hypothyroidism as well as with the health psychology literature. Therefore, whilst this research did not aim to generate theory or to apply deductive tools as a theoretical lens (Braun & Clarke 2006), this experiential research is not completely free of researcher interpretation.

Jacobson & Mustafa (2019) highlight the central role the researcher holds in generating and analysing data (Leibing & McLean, 2007; McLean, 2007). They highlight the multitude of factors which impact the way that research is approached, interacted with, and interpreted. These include the way that we see and interpret the world; our background, experiences, social identity, motivations for conducting research and our social position in comparison to that of our participants. They note that not only are there power relations to be examined, but that researchers are often outsiders without first-hand understanding of the unique social experiences.

Throughout this research, I have aimed to be reflexive about my own position to allow those who read it to better grasp how I produced the data (Finlay, 2002). In Chapter 1.2. 'Research Origins and Rationale' an overview of the starting point and rational for this research was presented. In Chapter 3.1 ('Rationale for qualitative approach: Development of researcher's epistemological and theoretical stance), reflexive examination took place, detailing the factors and experiences which shaped this research. The ways in which I have worked to ensure quality in this research were described in section 3.2. ('Quality issues in qualitative research), and the rationale for selection of analytic tool in 3.3. ('Selecting thematic analysis as an analytic tool for qualitative data'). Consideration of researcher positionality was provided in Chapter 3.11. ('Researcher positionality).

5.6. Implications for research and practice, and the role for Health Psychology

Implications for research

This research has highlighted Endocrinologists' views and experiences of psychosocial and self-management support in the context of patients with hypothyroidism in secondary care. It has found that Endocrinologists perceive patients with hypothyroidism as a heterogenous patient group with diverse support needs. It also found that Endocrinologists themselves have varied views, experiences, interests, levels of expertise and confidence, and perceived levels of support to address and manage the psychosocial concerns of their patients. Whilst a range of psychosocial concerns have been identified in the literature developed with patients with hypothyroidism, Endocrinologists are in a unique position whereby no current guidelines exist to guide them to support patients with this aspect of their care.

This thesis has made several recommendations for research, which are summarised in Table 1, below. Specifically, it recommends that a chronic (rather than acute) condition perspective is adopted in the management of hypothyroidism. Its also endorses the replacement of reductionist testing and treatment approaches (with patients as passive recipients of information) with asset-based, patient-centred models of care.

Table 1: Summary of recommendations for research

- Target heterogenous groups of patients with hypothyroidism to identity different concerns, needs and symptom clusters (e.g. the role of inflammation in persistent symptoms of Hashimoto's disease, the lack of information for patients with thyroid cancer)
- Widen the scope of research and intervention (e.g. to include epigenetics, nutrition, and physical activity)
- Address potential LT4 resistance, trial long lasting T3
- Involve patients and stakeholders from the outset to ask what is important to patients (beliefs, values, expectations)
- Co-produce and evaluate resources and interventions
- Include and support the charitable sector to build bridges between patients and the medical system
- Collaborate. Include Health psychologists, Endocrinologists, Exercise Physiologists, Physiologists, Pharmacists, Specialist Nurses in multi professional approaches
- Incorporate theory and exploratory frameworks. Include Communication theory (Lasswell, 1948) to develop shared meanings and understandings of the issues for patients and professionals; Social identity theory (Tajfel, & Turner, 1979) to examine conflicts and challenges to participants and patients' identities; and the 'Common-sense model of self-regulation' (Leventhal et al, 2003) to view patients as independent problem-solvers who actively process health information to create understandings that guide health-related decisions and behaviour.
- Embed PROMS and wellbeing measures validated for this patient group to measure quality of life (e.g. the ThyPRO, Watt et al, 2014)
- Review existing self-management interventions available to patients (e.g. self-management: Allegrante et al, 2019)
- Assess feasibility of adapting existing models/interventions (e.g. diabetes, cancer, TED)
- Create guidelines (e.g. NICE review) for addressing the psychosocial concerns of patients with hypothyroidism and to support self-management

To move the research conversation forward, Health Psychologists may play a role in supporting Endocrinologists and multi-professional teams to engage patients, particularly through the charitable sector, to identify the research questions that are important to them. In doing so, it is key to remain mindful of the diversity within this patient group. After identifying the psychosocial concerns of patients, a collaborative approach is required to co-produce and evaluate interventions to address these concerns and to support patients to develop the skills, confidence and experience to manage their health. An exploration of the feasibility of adapting existing self-management interventions from similar conditions for use with patients with hypothyroidism is required.

The areas identified in this thesis as important to patients through searching the patient-centred literature and interviewing Endocrinologists are summarised in Table 2 below. The development and evaluation of interventions to address these needs may support the creation of guidelines for professionals providing psychosocial care to patients with hypothyroidism.

Table 2: Suggested interventions to design and evaluate with patients

- Provide specific education targeted at patient subgroups (e.g. patients with Hashimoto's disease and thyroid cancer)
- Develop training for patients to find and utilise a range of information and resources
- Provide psychosocial support to address perceptions of disregard, responses to diagnosis and lifelong medication, managing emotions, adaptation to changed appearance (e.g. weight management, surgical scars), and to provide treatment expectation management and relationship support
- Promote positive social and psychological appraisals and wellbeing, promote personal control and resilience
- Develop communication strategies between patients and significant others (health professionals, family and friends and workplaces)
- Develop self-management interventions to promote recovery (e.g. adapt to changes in the ways that the body processes fat, adopt appropriate exercise for patients with symptoms of autoimmunity and patients with thyroid cancer)
- Address polarisation/build bridges between patients and the medical system particularly seen in online forums (e.g. through co-production)
- Retain a biological focus/remain mindful of endocrine pathology and ensure interventions work alongside, rather than replace optimal medical treatment

Implications for practice

To promote the inclusion of psychosocial and self-management support in the management of hypothyroidism, this thesis recommends that it is important to address the 'healthcare battleground' discussed in Chapter 4 ('Findings'). To do so, interventions to support clinicians, as well as to bring about change at organisational and socio-political levels are required. Health Psychologists may play an important role in providing research and evaluation, teaching and training, and consultancy to support the implementation of change to embed the evidence-based recommendations which result from the research streams described above.

The interventions which may support Endocrinologists to explore and address the psychosocial concerns of patients with hypothyroidism as identified in this thesis are summarised in Table 3 below. Specifically, the recommendation is made to develop and evaluate training for Endocrinologists in the theory and skills of psychosocial and self-management support. The outcomes of these training programmes may be used to develop NICE guidelines in this area.

Table 3: Interventions to support Endocrinologists to develop psychosocial and self-management support in practice

- Address attitudinal/behavioural variation towards patients' psychosocial needs (e.g. development of guidelines)
- Incorporate theory, e.g. Theory of Planned behaviour (Ajzen, 1991; 2002) to increase intention to implement psychosocial and self-management models of care (target perceptions)
- Support understanding of self-management theory and skill (avoid concerns about moralisation with shift away focus from 'lifestyle')
- Promote incorporation of psychosocial/self-management support whilst maintaining biological focus and validation of illness experience (skills training)
- Include support for difficult/emotional communication (e.g. unavailability of treatments, unresolved symptoms, self-medicating)
- Provide support for discussing mental health and psychosocial issues
- Support Endocrinologists to explore and address patients' lay beliefs (self-efficacy, understanding)
- Incorporate theory e.g. Self-determination theory (SDT) (Ryan & Deci, 2000; Deci & Ryan, 2012; Ryan & Deci 2017) to address mismatch in intrinsic and extrinsic motivation which may impact on clinician wellness and job satisfaction
- Reduce scepticism about PROMS (e.g. training, co-production)
- Provide opportunity to collaborate with other specialisms
- All healthcare clinicians offered training wo work with MUS
- Training also to be provided in primary care (NICE guidelines; medication reviews) to reduce flow to secondary care

The findings of this research also highlight the importance of addressing the wider barriers and facilitators to the adoption of self-management and psychosocial support. Health Psychologists may contribute useful skills in this area by applying the science and technology of 'Implementation Science' to improve the translation of evidence-based research into practice (e.g. Michie et al, 2011).

Implementation science is concerned with the translation of research into healthcare practice and policy, and the ways in which behaviour change is facilitated in multi-level systems (Michie & Johnston, 2017). The implementation of psychosocial and self-management support may be supported by drawing upon theoretically driven behavioural frameworks such as the 'Theoretical Domains Framework' which recognise and target social and environmental (as well as cognitive, affective) influences on health professional behaviour (Atkins et al, 2017).

The findings of this thesis have identified a range of organisational (healthcare) level factors which may be addressed to examine their influence on the adoption of psychosocial and self-management support for patients with hypothyroidism in secondary care. These are summarised in Table 4 below.

Table 4: Recommended organisational (healthcare) changes to promote implementation of psychosocial and self-management support for patients with hypothyroidism

- Offer reviews and psychosocial/self-management support from diagnosis in primary care
- Develop referral pathways for patients with hypothyroidism
- Incorporate patients and multi-disciplinary professionals as assets in care planning and control of symptoms
- Support and fund the charitable sector to build bridges and trust and to create unified, expert messaging
- Value patient-centred care with patient needs, preferences and values at the centre
- Highlight and address paradoxical barriers and incentives to patient centred care and activation
- Address the mismatch between promoting new healthcare paradigms and the realities of practice (reductionism/risk-aversion)
- Promote task identity (creativity, personal growth, engagement and use of talent) to prevent against diminished motivation and burnout amongst clinicians and promote clinician wellbeing, (i.e. promote skills and confidence, update research)
- Reduce fear of blame and promote positivity and hope

Similarly, this thesis has identified a range of socio-political level factors which may be addressed to examine their influence on the adoption of psychosocial and self-management support for patients with hypothyroidism in secondary care. These are summarised in Table 5 below. Health Psychologists and multi-professional colleagues, as well as patients and the charitable sector should work alongside commissioners and policy makers as agents of change (Garratt, 2017) to reduce the gaps of health and well-being, care and quality, and funding and efficiency as set out in the Five Year Forward View (NHS England, 2016).

Table 5: Recommended socio-political changes to promote implementation of psychosocial and self-management support for patients with hypothyroidism

- Address struggle to devolve ‘power’ to patients (address scientific unknowns, potential risks)
- Reduce boundaries between organisation/specialism divides
- Address dismissal and disregard of patient concerns in healthcare system
- Recognise the value of asset-based models
- Recognise threat of asset-based models to the healthcare/public health status quo
- Incorporate implementation science and knowledge mobilisation to implement the ‘personalised care model’ in the NHS Long Term Plan (2019)
- Address uncapped rises in generic medicines in the UK
- Address health inequalities and patient safety/harms created by cost-based restrictions to services
- Provide resources and funding to further the research conversation and promote patients choice/clinician autonomy
- Raise hypothyroidism on the political agenda (levothyroxine is the third highest prescribed drug in the UK; NHS Digital, 2017)
- Psychosocial and self-management support within healthcare requires a whole system collaborative approach to improve performance and develop enhanced outcomes

5.7. Conclusion

This research has created novel findings that patients with hypothyroidism have unmet needs for information and support from the point of diagnosis, but that Endocrinologists perceive a lack of time, training, service provision and support to facilitate psychosocial and self-management models of care.

Patients, Health Psychologists, Endocrine Nurses, Dieticians, Pharmacists, and experts in the charitable sector are valuable assets to Endocrinology and may contribute to self-management programmes and clinician skills training to address gaps in provision for those in need. Self-management support should not be provided in place of medical treatment or service improvement, and the needs of those for whom standard treatment may be ineffective should be addressed.

Addressing the cost of treatments (specifically, unregulated rises in generic medications), funding quality research (e.g. trials of long-acting LT3 targeting specific hypothyroid patient subgroups, alongside interventions to address patient-identified psychosocial concerns), building bridges between patients and the healthcare system (through co-production and inclusion of the charitable sector) and increasing innovation and autonomy in healthcare may reduce barriers to the implementation of psychosocial and self-management models of care. The value of asset-based models of working to meet the changing demands upon healthcare should be recognised, alongside the threat that they may pose to the socio-political status-quo. NHS staff need to be supported in a culture which promotes creativity and innovation and reduces burnout and fear blame, especially those caught in the middle of opposing healthcare paradigms.

The findings presented in this thesis recommend areas of change at all levels of the healthcare system to improve outcomes for patients with hypothyroidism and for the clinicians treating them. A whole-systems approach is needed to support Endocrinologists to place patients with hypothyroidism at the centre of their care.

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Appendix A: Ethical approval

Faculty of Health & Applied Sciences
Glenside Campus
Blackberry Hill
Stapleton
Bristol BS16 1DD

Tel: 0117 328 1170

UWE REC REF No: HAS.18.10.038

19 September 2019

[redacted]

Dear Michelle

Application title: Exploring Endocrinologists' attitudes and perceptions towards psychosocial self-management support for hypothyroidism in the UK

I am writing to confirm that the Faculty Research Ethics Committee are satisfied that you have addressed all the conditions relating to our previous letter sent on 31st October 2018
and the study has been given ethical approval to proceed.

http://www2.uwe.ac.uk/services/Marketing/about-us/doc/one-page-portrait-UWE-word-doc-with-colour-logo.docx

The following standard conditions also apply to all research given ethical approval by a UWE Research Ethics Committee:

1. You must notify the relevant UWE Research Ethics Committee in advance if you wish to make significant amendments to the original application: these include any changes to the study protocol which have an ethical dimension. Please note that any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee. Amendments should be requested using the form at http://www1.uwe.ac.uk/research/researchethics/applyingforapproval.aspx

2. You must notify the University Research Ethics Committee if you terminate your research before completion;

3. You must notify the University Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.

The Faculty and University Research Ethics Committees (FRECs and UREC) are here to advise researchers on the ethical conduct of research projects and to approve projects that meet UWE's ethical standards. Please note that we are unable to give advice in relation to legal issues, including health and safety, privacy or data protection (including GDPR) compliance Whilst we will use our best endeavours to identify and notify you of any obvious legal issues that arise in an application, the lead researcher remains responsible for ensuring that the project complies with UWE's policies, and with relevant legislation https://intranet.uwe.ac.uk/whats-happening/sites/gdpr/updates/pages/research-and-gdpr-compliance-update-08-may-2019.aspx. If you need help with legal issues please contact safety@uwe.ac.uk (for Health and Safety advice), James2.Button@uwe.ac.uk (for data protection, GDPR and privacy advice).

Please note: The UREC is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the UREC and its committees.

Please remember to populate the HAS Research Governance Record with your ethics outcome via the following link: [redacted]

We wish you well with your research.

Yours sincerely

Chair
Faculty Research Ethics Committee

Appendix B: Participant information sheet

Participant information sheet for semi-structured Interview

Invitation

The study you are being invited to take part in is part of a professional doctorate in health psychology at the University of the West of England and is supported by the British Thyroid Foundation.

This semi-structured questionnaire asks about your views on the management of hypothyroidism; the involvement of patients in decisions around their care, and the things that may affect the ways that hypothyroidism is managed.

What is the project's purpose?

Despite the known efficacy of treatment for hypothyroidism, unknown numbers of patients report residual physical, psychological, cognitive, and social symptoms. Recommendations in the research literature carried out with hypothyroid patients include a need for psychosocial and self-management models of care to be developed to improve health-related outcomes. This is supported by the NHS Five Year Forward View which acknowledges the need to support people to manage their health and care.

Little is published about the provision of supportive models of care for people with thyroid disorders in secondary care, or the tools and techniques currently being used by Endocrinologists with their patients. This semi-structured interview aims to learn more about your views on the medical care you provide to people living with hypothyroidism; and about the available approaches to the management of their condition.

Why have I been chosen?

A survey has previously been sent to all Endocrinologists who are members and associates of the British Thyroid Foundation. All survey recipients have been invited to take part in semi-structured interviews as we would really appreciate your views on this topic. A smaller number of Endocrinologists have been directly invited to take part by other participants via a snowballing sampling technique.

What will happen if I agree to take part?

You will be asked to take part in a semi-structured interview lasting between 30 and 45 minutes. This is likely to be on the telephone depending on where you are in the UK.

What are the possible benefits of taking part?

It is hoped that this research will bring new insights into the management of hypothyroidism, which currently effects between 2% to 5% of people living in the UK. This research may help to underpin the future development of psychosocial and supportive interventions for patients living with hypothyroidism.

Will my taking part in this research be kept confidential?

All information that we collect about you in this research will be kept strictly confidential.

The interviews will be audio recorded and transcribed using Microsoft Word. Interview transcripts will be anonymised and stored online, protected by passwords and other relevant security processes in line with the University of the West of England data management protocol. Once interviews have been transcribed and analysed, audio recordings will be securely destroyed in line with the University of the West of England data management protocol.

Hard copies of consent forms and interview transcripts will also be stored securely and only accessible to the research team. Reporting of interview data will be done in an anonymised way and no identifying such as name or employing institutions data will be reported.

Data collected may be shared in an anonymised form to allow reuse by the research team and other third parties. These anonymised data will not allow any individuals or their institutions to be identified or identifiable.

Can I choose to withdraw from the study?

You may choose to withdraw from the study without giving a reason. You are free to withdraw from the study up to two weeks after the interview which will give you additional time to ask further questions about the research after receiving the debrief at the end of the interview. If you choose to withdraw, the audio recording of your interview will be securely destroyed without being analysed.

Who has ethically reviewed this research and who can I contact if I have any concerns?

This project has been ethically approved by the University of the West of England Research Ethics Committee. If you have any queries or complaints about this study, you may contact researchethics@uwe.ac.uk or Tel: +44 (0)117 32 81170. If you have any concerns regarding the needs of your patients as a result of this project, please contact the British Thyroid Foundation on 01423 810093 for support and guidance.

Who can I contact for more information?

For more information, please contact the corresponding researcher: [redacted]

Appendix C: Consent form

Corresponding researcher: Michelle Griffiths
Department of Health Psychology
Contact details: [redacted]
Primary Researcher status: Stage 2 Trainee Health Psychologist
UWE ethics contact: researchethics@uwe.ac.uk

Participant Consent Form: Qualitative Interview

Study Title: Exploring psychosocial and self-management support for hypothyroidism: A mixed-methods study in the UK

Purpose of the study: To explore your views on the management of hypothyroidism; the involvement of patients in decisions around their care, and the factors impacting the ways that hypothyroidism is managed in secondary care.

Please initial statement

1. I confirm that I have read and understand the information sheet for the above study.

2. I am aware of the corresponding researcher and UWE ethics department contacted details to ask any additional questions I may have.

3. I understand that my participation is voluntary and that I am free to withdraw for 2 weeks after the interview without giving any reason, and without any consequences or penalty.

4. I am aware that any data collected about me will be stored securely and that no individual identifying information will be reported.

5. I have considered any potential risks associated with taking part in this research.

6. I understand that data collected during this study may be looked at by designated individuals from the University of the West of England. I give permission for the researcher’s supervisory research team to access my data for the purposes of this study.

7. I understand who will have access to personal data provided, how that data will be stored and what will happen to the data at the end of the project.

8. I understand how this research will be written up and published

9. I understand this project has been reviewed by, and received ethics clearance through, the University of the West of England Research Ethics Committee.

10. I agree to anonymised data collected in this study to be shared with other researchers to be used in other research studies.

11. I agree for data collected in this study to be anonymised and shared with other researchers, to be used in other research studies.

12. I agree to take part I this study.

13. I agree for my contact details to be kept in a secure and encrypted database for the purpose of contacting me about follow ups to this research. I understand this does not oblige me to participate further.

dd / mm / yyyy

Name of Participant

Date

Signature

dd / mm / yyyy

Name of person taking consent

Date

Signature

Appendix D: Semi-structured interview topic guide

Introduction:

Thank you for agreeing to take part in this interview. We are conducting this study to help us understand how hypothyroidism is managed in secondary care, and to learn about opportunities to support patients with hypothyroid symptoms. Some of the questions may appear to be quite similar or obvious to answer but we are trying to understand the topic from a variety of perspectives so bear with me, take your time and answer as frankly as possible. Are you happy to get started?

1. (Managing expectations) how many of your hypothyroid patients struggle with symptoms that are difficult to resolve, despite returning to normal population reference ranges?

2. Population characteristics: Are there distinct subgroups of people with hypothyroidism (such as those who have been treated for cancer, or those with autoimmune thyroid diseases) who are more likely to experience residual symptoms?

3. Why do you think there are patients who appear to remain ’dissatisfied’ with their treatment? What percentage do you believe this to be?

4. How do you feel when patients remain dissatisfied with their hypothyroid symptoms and treatment?

5. (Should we better manage patient’s expectations to expect residual symptoms as with other medical conditions?)

6. Medical management: Are clinical guidelines and available treatments sufficient to meet the needs of all hypothyroid patients?

7. Psychological management: Do you feel able to help your patients to manage the emotions and stresses in relation to hypothyroidism and its treatment?

8. Do you feel able to identify hypothyroid patients who may need further psychological and emotional support?

9. What other services are available to support your patients to manage the emotional impact of hypothyroidism?

10. Behavioural management: What patient skills or lifestyle changes do you think have the greatest impact on health outcomes for hypothyroidism?

11. How confident to you feel to address these and to collaborate with patients to work towards healthy goals?

12. Do you feel able to meet the informational and educational needs of your patients (for example to implications of over or under replacement? dietary advice, fatigue management)?

13. What tools and resources are available to you to inform and educate your patients about managing their condition?

14. Do you think it is important for patients to self-monitor their hypothyroidism? Do you teach patients the meaning of their blood test results?

15. Do you refer patients to other specialisms for residual symptoms? Examples? (sex hormones, vitamin deficiencies, cardiac, rheumatology, hepatology

16. Do you think that additional skill sets, or multi-professional approaches are required to support Endocrinologists to help hypothyroid patients to manage their condition?

17. Do you think that changes will occur in the future regarding the ways that hypothyroidism and its treatment are managed?

18. Thank you for answering my questions… is there anything else that you think is important to note in this subject area?

Appendix E: Debrief form

Interview debrief form:

Exploring the views of Endocrinologists towards psychosocial and self-management support for hypothyroid patients: A mixed methods study in the UK.

Further details of the research

The research you just participated in was part of a study to examine the views of Endocrinologists towards psychosocial and self-management models of care for hypothyroid patients; to enquire whether embedded or structured psychosocial and self-management support for hypothyroid patients exists in secondary care that is currently unreported in the literature and to explore the barriers and facilitators to the provision of a psychosocial and self-management model of care.

The rationale for this study is outlined below:

Hypothyroidism is a costly and growing problem currently affecting between 2% and 5% of the population in the UK, and Levothyroxine is currently the third most prevalently prescribed drug in the UK. Despite the known efficacy of treatment for hypothyroidism, unknown numbers of people report continued symptoms, loss of daily role function and impaired employment; and numerous, often debilitating residual physical, psychological, cognitive, and social symptoms have been reported in the literature.

Research carried out with people with thyroid disorders recommends the development of psychosocial and self-management models of care to improve health and quality of life outcomes for
hypothyroid patients.

In the published literature of clinician's attitudes towards 'patient activation' (providing patients with the knowledge, skills and confidence to manage their own health), varied views have been reported regarding the roles that patients should take in their own care. Broadly, clinicians are more likely to support patients to make behaviour and lifestyle changes in accordance with clinical advice. However, clinicians have found supporting self-management to be more problematic when it consists of patients making independent judgements or independently seeking information or treatments that may contradict clinical advice.

The aim of this research was to explore your experiences of the barriers and facilitators to providing psychosocial and self-management models of care to hypothyroid patients in secondary care so that we can learn more about the opportunities to develop interventions based on the recommendations in the patient literature.

Further information

There is a possibility that the current research findings may be published in a scientific journal to aid general greater understanding of managing hypothyroidism.

If you decide you would like to withdraw from this research, you can do so up until two weeks from today.

To withdraw from the study or for further information please contact:
[redacted]

If any of the topics discussed today have caused any you any concern or you would simply like to access further support, please contact the British Thyroid Foundation on 01423 810093.

Thank you for taking part.

Appendix F: Interview coding

Interviewer: The first question is whether you think that hypothyroidism is a chronic condition in terms of monitoring or management, or whether it's likely that symptoms will go on when peoples' blood test return to the population reference range?	
Interviewee 2: So (…) I think in a sub percentage maybe around 10% to 15% appear to have persisting symptoms despite returning to the reference range.	**Belief in biomedical reason for ongoing symptoms**
Interviewer: Do you think that there is a particular subgroup of people such as those who've been treated for cancer or those with autoimmune thyroid diseases who are more likely to experience these residual symptoms?	
Interviewee 2: I don't know that but from what I can see (…) it's less likely to be the people treated for cancer and more likely to be people who are treated for mild hypothyroidism.	**Those with mild hypothyroidism may be more symptomatic.** **Interesting that did not identify cancer – cancer salient to me due to proof Doc placement where I saw this was an issue… why not here? Thyroid cancer predominantly dealt with in oncology… Doctor I says they see a lot of patients treated for thyroid cancer… also did not identify. Contradicts my assumptions.**
Interviewer: Right okay uh this is a really open question bear with me, why do you think there are patients who remain dissatisfied with their treatment?	
Interviewee 2: It's likely to be a mixture (…) sorry [unintelligible 00:01:39] in the background (…) of two things probably one is some patients who actually their symptoms are not related to the thyroid, their symptoms are quite vague especially if they only have very mild changes those might be the group that you'd expect would not really respond very well to changes in therapy but might respond to a more holistic approach. The second group, which I have an emerging theory about would be those in whom they um seem to benefit more from having a combination of T4 and T3 and are therefore somehow sensitive to being replaced with thyroxine on its own o I would like to think there is a T3 responsive group and there is a non-T3 responsive group, if you want to look at it that way.	**Mild vague symptoms may not be thyroid. One group. Holistic approach may be better than changes in thyroid medication for this group.**
Interviewer: Yeah ok so how do you feel when patients remain dissatisfied with their hypothyroid symptoms and treatments? I think people are vary, vary much in their practice, so the responses have been quite different to this .	**Less frustrating for doctors when they have the option of trialing personalised medicines.**
Interviewee 2: Some people find it very frustrating and depressing but because we have a clinic in which we do offer them alternatives, I think that's much easier to deal with than doctors who don't really have that option. I'm reasonably comfortable with those patients, we treat them fairly regularly and comfortable trying alternative options because at the end of the day, it's only a trial of other forms of common replacement that will tell you which group they fall into.	

Interviewer: Do you think we should manage patients' expectations earlier as to the efficacy of T4 treatment? Do you think nationally, there's a problem with patient expectation? **Interviewee 2:** I actually don't know the answer to that one. I'm very keen that we, in the end, do the right trial to address that question because most of the studies that have been done at this point with T3 have not probably been done in the right way and the results have been disappointing. When we are able to replace some closer to normal physiology, then we'll be able to sort out the wheat from the chaff a little bit then answer your question because we certainly have some patients who are delighted and they say they're pretty much tback to normal but There are other people where it's really only 20% or 30% and they go "Well, do you know what?" and then other people that you wish you'd be more cautious about your expectation management I think generally correct, you have to be careful about their expectations, especially those people who are not profoundly hypothyroid at the beginning where it started from a mild position but there's certainly a percentage who've had significant benefit. **Interviewer:** Great okay. Onto a different strain of questions now (...) Do you feel able to help your patients to manage the emotions and stresses in relation to their hypothyroidism and its treatment? **Interviewee 2:** Well, only to a very limited extent. I do discuss other features that are going on. The patients, in general, don't want to talk about that, they say they want to focus on the biological elements. We all have discussions about other stuff that's going on for them, discover what might be other major stresses in their life, financial, bereavement, relationship, that kind of thing. They need to be aware of that and continue to discuss those things, continue to encourage them to work on those sides as well as on the biological side. That's partly if you like a bit of expectation management there too. I really don't think in the time I have available that I can do the best. What I think I can do is something we've discussed, is to help legitimise more holistic approaches when people are very biologically focused I'll say, "Right, that's fine. I will deal with the biology, but I think it'll help you to have a wider approach to your therapies, alternative therapies, complementary therapies, holistic approaches, that kind of thing which I can't provide." **Interviewer:** Do you know of any other services or places that you can refer your patients to help them with this aspect of the condition or this aspect of holistic approach? **Interviewee 2:** There's a simple answer to that question, Michelle.	**Belief that clinical trials are not sufficient quality.** **Manage expectations of the mildly hypothyroid group who may not benefit from lone or combination treatment.** **Belief that there are different patient group and some benefit from combination treatment.** **Limited ability to address psychological impact.** **Patients reluctant to discuss emotions and want to focus on biological aspects. Encourage patients to work on this (link to expectation management and interview 1; want a fix without having patient input).** **Lack of time for holistic approach but does try to ask about what's going on in patient's life. Interview 1 did 'not have the will' to change to this approach.** **Belief in legitimising holistic integrative approaches to therapies.** **Does not believe that these patients have a psychiatric reason for persistent symptoms (link to T.Watt, debates about biological/psychological causes old; need to move forward to improve patient experience). This dr tries to promote a holistic approach but uses 'belief'. Interview 1 wants to make them feel listened to but does not have such belief or willing to trial personalised medicines approach.**

Interviewer: [laughs] Yes I see.	
Interviewee 2: There is a liaison psychiatry service who will help diagnose psychiatric disease you know significant depression but in my experience, very few of these people have a diagnosable psychiatric disease.	**Sympathetic approach (listening, discussing, not just saying 'no') to improve outcomes. Patients can stop fighting and start healing (promote holistic approaches alongside not instead of medical treatment). KEY POINT link to psycho-oncology and integrative medicine. Complimentary not alternative.**
Interviewer: So then what skills or lifestyle changes do you think have the greatest impact on the health outcomes for the patients that you see? what lifestyle changes may patients who've been successful have brought into the management plan with them?	**Being believed, listened to and not belittled. Not having to fight to be heard or to try options that might improve your biological health are more important than a particular complimentary therapy (e.g. meditation) when you are still fighting for your health.**
Interviewee 2: I'm not sure if I can be very specific about that. I certainly think and it is not quite the answer to the question, but it really helps them to be sympathetic anyway. A lot of people that I see are very angry have fought for a long time trying to get a hold of drugs etc. just giving them the opportunity, listening to them, helping them discuss instead of saying, "The answer is no. What is your question?" It's immensely helpful. It's an enormous relief for people that they can actually stop fighting and start healing if you want to look at it that way.	
Interviewer: Fantastic.	
Interviewee 2: An acknowledgment of listening is very important listening to all aspects and not belittling small ones unless **[unintelligible 00:08:54]**. Listening support is definitely helpful. More specific than that, I don't think I can narrow it down. I'm tempted to just say to the patient, "I'm for whatever you feel gives you more energy, so long as it's not going to be harmful, I would strongly be supportive of." Some people, they do a little bit of breathing exercise i'm not sure that's a big thing, a few people engaging in other complementary therapies. Some people try meditation or mindfulness I don't think I can identify one specific one, my rough shot at it is it is a more holistic listening and supportive approach.	**Collaboration not confrontation.** **Need for a practitioner to support collaboration with patients and practitioner in the service (link to interview 1: get patients involved from outset to see what they want and need).**
Interviewer: The next few questions have been covered by that. I might just tell you what they are and see if there's anything you want to add to that last response. The next questions really were about how confident you feel to collaborate with your patients to work towards healthy lifestyle goals. What you've described as your communication style and your approach actually shows your collaboration style. We'll move on—	**Listening, validating, 'keeping the door open' ro a biological explanation (link to interview 1; people hope for a biological explanation to avoid labels of 'blackout' feeling). Patients less likely to engage if they feel you are saying it is all in their head (link to backlash against ME PACE study - exercise or CBT helps recovery from ME - patients felt it doubts biological basis of disease or symptoms). Will engage more about lifestyle or complimentary approaches if validate their experience.**
Interviewee 2: I'm certainly willing to do that and to do it in a collaborative way rather than a confrontational way. I would	

certainly be helped if I had a practitioner who is better at it than me that work in the service. **Interviewer:** Similarly, do you feel able to meet the informational and educational needs of your patients? I guess they come in with lots of different questions around fatigue management, dietary advice, implications of under or over replacement. Do you feel that you have the time and the ability to work with patients for these informational needs? **Interviewee 2:** Again, I think the answer is partial in the sense that what people they benefit from is listening and an explanation and keeping the door open that there may be a biological explanation. Basically, that actually relaxes people a little bit to consider other things because it's like, "If you think I'm mad, I'm not going to have a conversation with you," but if I give them the legitimacy which I think is legitimate, that there may be a biological reason why they're not feeling well. That helps me engage more with other aspects. It gives me a bit more of a mandate to discuss those things. **Interviewer:** Yes. Now i'm looking at some of the tools and resources that are available to you to inform and educate your patients about managing their condition. One could be showing them their test results or the DEXA scan, what resources do you feel that you do have or maybe don't have to help people to learn more about their condition? **Interviewee 2:** Yes. I very much want my patients to feel I'm being transparent and that there's no smoke and mirrors happening here. That's particularly the case when what I'm trying to discuss is the risks of over replacement. It's so important to me that it is collaborative. Things like the DEXA scan is an illustration of what might be, the thinning of their bones, and it's potentially a side effect. The blood test results are showing that graphically with green and red areas showing what the normal range is begins to help people understand how farther away they are from the rest of the population. I find those tools to be helpful and also the fact that you've explained them from the computer suggest that it's not an edited version you know what I mean you're seeing what I am seeing. I think that increasingly helps people feel that they're not being fobbed off and hidden to as well as trying to feel that they're being respected partners and understanding this process. **Interviewer:** Thank you. This is great. Do you refer patients to other specialisms for unexplained residual symptoms? Um examples, vitamin deficiencies, cardiac, rheumatology, CFSME you know where do you commonly refer to outside of your office for this particular group?	**Clarity (no smoke and mirrors), collaboration, transparence; helps with open trusting relationship to discuss issues like over-replacement. Trust of doctor (interview 1 - trust is not offering open choice of medication but sticking to your medical knowledge and beliefs). Different interpretations of trust. Trust me im the expert versus collaborative trust.** **Education e.g. of scans, graphs** **Not being fobbed off. Patients as respected partners in collaborative process. Fostering patient understanding of the process.** **Does not see this patient group as CFS/ME (opposite to interview 1).** **Knowledge of CFS criteria and differences with this patient group.** **Reluctance to attribute to lifestyle or unexplained symptoms.**

Interviewee 2: And the answer to that question is that I rarely refer unless if it's a symptom that is very persistent and I want to make sure I'm not missing biology there. We don't really have, as far as I'm aware, a well-established CFS service. I'm not sure to what extent they will entertain these people. They are different from CFS in the sense that the CFS patients, well, they manifest differently. The thing is fatigue, they can't get out of bed and they're lucky if they get out of bed one day. For most of the thyroid patients, it's more they're not themselves, they can't think straight, they can't concentrate, they can't perform well, but very few of them, I don't think anybody, is bed bound. The little bit I've done with CFS, there was quite a few people who are pretty much bed bound actually. These people do get up but they find it difficult to function at the level they want to function at.They find it difficult to do their jobs, or if they do their job, they come home and they're exhausted and lie down but they're not you know, I'm feeling that probably many of them would not qualify as having CFS by CFS criteria. I haven't at the moment found somewhere else. If somebody had a particular symptom, let's say, for argument's sake, diarrhea or something like that that I thought well like "Well, this doesn't really fit," or particularly abnormal blood test that I wouldn't expect I would very much want to rule out organic disease I don't want to miss the fact that someone's got an underlying cancer or something like that that I am not understanding. I don't think you can discuss the kind of issues we're talking about now unless you're very confident that you're not missing another diagnosis.	**Need for a specialist nurse or Health Psychologist role in the service. More detail in educating patients and managing the 'less explained' aspects. Risks and benefits, informed discussion. More time for the patient allowing the doctor to see more patients. Nurse to spend more time discussing tests and treatments and health psychology for health improvement/emotional/social (less endocrinology) aspects.**
Interviewer: Given that lack of referral pathway, do you think there are additional skill sets or multi-professional approaches that would support endocrinologists to help their hypothyroid patients to manage their conditions?	
Interviewee 2: Yes, very much so. People talk about an Endocrine Nurse role along with a Health Psychologist role here. It's a balance between dealing with the organic and the less explained. I'm reasonably comfortable at managing the medication, adjusting the medication, discussing the issues. It would be helpful to me, I could see more patients, if, for example, there was an endocrine nurse who said exactly the same thing but went into it in more detail. I think we could benefit more people if there was a health psychologist who could deal with the wider issues that are not obviously endocrinology, if you like. An endocrine nurse experienced in this area could discuss the benefits and the risks and how we do the dosing and how we're going to think about testing it, what tests we're going to do, and all that kind of thing as well as I could and spend more time with people. It's more of a health psychology role to go into the wider aspects of their life and how they can get a better outcome overall by addressing other aspects of their life.	**Hope for change in the future: alternative forms of therapy, recognition of those who do not respond to therapy and to design better clinical trials.** **Critical of the existing clinical trials** **Hopeful that we 'can sort out' the dissatisfaction of patients (still focusing on the issue of T4/T3 combination therapy)** **Hope for slow release T3 to 'get a significant proportion of people better'.** **New theories about treating those with mild disease (it might make things worse due to DI02 enzymes increasing T4 ratio)**
Interviewer: Final question. I think we're just about making it to three o'clock. Do you think the changes will occur in the future regarding the ways that hypothyroidism and its treatments are managed?	

Interviewee 2: Well, number one, I very much hope so. Actually, two days ago, the draft NICE criteria came out. They do very clearly leave the door open that there are some dissatisfied individuals and they acknowledged this and they acknowledged that some may need alternative forms of therapy. There is a meeting coming up which is a joint meeting between the American, European, and British thyroid associations, it's going to happen in London, to look at the new science around this. Particularly, the idea is to get a consensus together and to design better trials.

Interviewer: Excellent.

Interviewee 2: There are theories as to why the previous trials have failed. I think there's some biological reasons why that could be the case. I'm led to understand that the NICE criteria will lead to potentially some funding for some more research in this area. I think that we can sort this out. Increasingly, the view that a slow release T3 would be very helpful both in terms of getting the level right and in terms of being able to monitor very accurately. I'm not sure that it is essential for the patients, but it's much easier to know that you've restored the natural level Is which is what you dont get with the current dosing. I'm fairly optimistic that if we go in those directions, developing a slow release T3, then treating people in a proper RCT with the right outcomes with slow release T3, I think we'll get a significant proportion of people better. There was a biological reason why thyroxine actually makes people with mild hypothyroidism worse because of the deactivation of their own hormones but we've yet to prove that in humans.

Interviewer: The deactivation of their own hormonal function, you mean for people with—

Interviewee 2: The enzyme that activates T4 to T3, the deiodinase enzyme, and there is quite good evidence that T4 actually inhibits that enzyme. When you take T4 alone, you get a disproportionately high level of T4 in your blood in terms of the T4 to T3 ratio. What that may be doing is it still feeds back to the pituitary, so the pituitary says, "That's fine." If there's evidence that the pituitary enzyme is not inhibited, there is the enzyme in the periphery in the rest of your body is inhibited so it's eventually the more you take of the thyroxine, the less you're getting because less of it is converted.

Interviewer: Interesting.

Interviewee 2: It's a natural way of protecting the tissue from too much thyroid hormones because they don't expect-- Biologically, we weren't developed to eat thyroxine. This may be an explanation but it remains to be proven.

Interviewer: Fantastic. Okay, so thank you for answering my questions. Is there anything else that you feel is important to note in this subject, or area, or that I may have missed out or not, or misrepresented or anything?

Interviewee 2: There's a point about the anger that's been generated around the cost, and therefore, the lack of availability, and therefore, the lack of experience, has made

The cost of T3 has led to a lack of availability and a lack of clinician experience and resulting in anger that did not need to be the case. People have felt denied.

the situation about a hundred times worse than it needed to be because people feel angry and denied. That's an important amplifying factor in this problem. **Interviewer:** Possibly what we need to keep in mind if a slow release T3 is developed that we somehow keep it affordable to the UK [laughs] **Interviewee 2:** 100%, absolutely. There's no point if we can't do that, yes. **Interviewer:** Wonderful. Okay. Well, thank you. Thank you so much for taking time part.	

Appendix G: Collating codes by Interview (example excerpt)

Generated in interviews 1-5

General attitude towards condition:
Heterogeneity of thyroid subgroups:
Reasons for persistent symptoms:
How Endocrinologists feel
Psychosocial interventions
Trust/belief in scientific literature
Expectations:
Referrals
Need for a multidisciplinary approach?
Anticipated Changes to treatment
Engaging in changed practice (sees results) but need to have a will to change practice
Trust in doctor and patient (empowerment)
Other thoughts
Open Vs closed door medicine
Experiences/competency of doctor
Cause of patient stress/distress (role of medicine in this)

interview 1a	Interview 2b	Interview 3c	Interview 4d	Interview 5e
Focus on persistent symptoms and link with unexplained symptoms. Patients wanting treatment so that symptoms cannot be attributed to being 'all in their mind' to avoid the threat of this. Dangerous role of social media/influence of 'others' **General attitude towards condition:** should be simple, symptoms should subside Unexplained symptoms Looking for physical causes Don't want it to be seen as all in the mind	**Reasons for persistent symptoms:** Those treated for mild hypothyroidism (problem is not the thyroid; some other cause); vague symptoms (more like chronic fatigue) Belief that in come cases, treatment is sub-optimal as some patients require T4/T3 combination therapy "listening and an explanation and keeping the door open	**General attitude towards condition:** Requires management and adjustments and monitoring, manipulation within wider reference range the treatment is quite long it requires constant and regular monitoring dose adjustment and so on as well as clinical evaluation. I think again the vast majority of patients are fine when the thyroid function is within the reference range **Heterogeneity of thyroid subgroups:**	**General attitude towards condition:** Micro managed at GP level, dogma in medicine, battleground **Heterogeneity of thyroid subgroups:** Permanent hypothyroidism (thyroid removed, RAI for cancer; progressive autoimmune thyroiditis) Transient cases where thyroid can recover **Reasons for persistent symptoms:** Symptoms at best are vague and non-specific	**General attitude:** Dissatisfied patients are up to 15% but when consider this is the third most prescribed drug in the UK, this is a very large group **Heterogeneity of thyroid subgroups:** Heterogeneity between those who find it difficult to manage and those who do not Autoimmunity leads to higher dissatisfaction/continued symptoms. Autoimmunity increases severity. WE don't know why that is. Genetic polymorphisms **Reasons for persistent symptoms:** Genetic polymorphisms Do not feel better because not the thyroid Lack of tissue level biomarker

Need for diagnosis drives belief that thyroid is cause of symptoms Euphoria (weight loss) when thyroid hormone taken to excess Risk of excess/unlicensed treatment (morbidity/long term health outcomes) **Heterogeneity of thyroid subgroups:** Autoimmunity has more symptoms (in literature and does not question this) Role of inflammation **Reasons for persistent symptoms** Unexplained symptoms with normal biochemistry (wider patient group in literature) Not due to suboptimal thyroid hormone replacement (combination T4/T3 not effective) Patient group is a tiny fraction (nowhere near the 15%) 'Expressed dissatisfaction' rather than persistent symptoms Over investigation/diagnosis (about 50%) and treatment of normal/subclinical patients at GP level Thyroid is not the cause of the symptoms in some	that there may be a biological explanation". Most would not meet CFS criteria (from professional experience in this area), manifests differently (lack of functioning versus bedbound) **Psychosocial interventions:** Those treated for mild hypothyroidism (problem is not the thyroid; some other cause); vague symptoms (more like chronic fatigue) may respond more to a holistic approach: support, promote approaches to help feel better (if not harmful) "What I think I can do is something we've discussed, is to help legitimize more holistic approaches when people are very biologically focused. I'd say, "Right, that's fine. I will deal with the biology, but I think it'll help you to have a wider approach to	Some have residual thyroid function, some have reliance on thyroid replacement. People with cancer have had parathyroid removal, high doses of radioactive iodine Autoimmunity creeps up over a long time (over years) Thyroid supplementation versus complete replacement **How Endocrinologists feel** Systematic, clear, boundaried **Reasons for persistent symptoms** Threshold for treating too low (GP level, treating people with fatigue/symptoms with only mild changes in biochemistry) which then leads us to the questions as to A, "Is it because the thyroid hormone isn't working?" B, "Is it because the symptom was never related to the thyroid in the first place?" Because subclinical hypothyroidism is so common, this was just an incidental finding.	Thyroid can become the focus of all symptoms in people with hypothyroidism **Patients 'micro-managed in primary care' (being made to change doses based on blood tests). A source of frustration for patients.** Cost of T3 stops individual trials Trials were never done systematically NHS barriers (tests for T3) to help monitor condition Patient have to fund) **Other thoughts** Lots of patients source medication and fund trials privately, they are the more educated and affluent Anecdotally, the vast majority of patients seem to feel a lot better on it. (link to Taylors epidemiology paper) **Changes in treatment:** Endocrinologists do not se most people with hypothyroidism unless there is a problem (me does this lead to an underrepresentation of persistent symptoms in the hypothyroid population?)	Overreliance on TSH as biomarker (link to Toft paper) Many patients have tried everything they can to feel better **How Endocrinologists feel** **Trust/belief in scientific literature:** So um the question is how much of it because we've got it wrong, and it's a misclassification and how much of it is because some people are more susceptible to the risk of the symptoms. I don't think that we know the answer to that. Science showed that T4 could convert to T3 and that people preferred T4 **Limitations of research papers underpinning clinical guidelines (rationale for doctors keeping an open mind). Wrong dosing of combination therapy so that people reported no change or became thyrotoxic. Clinician knowledge and critical awareness of the research - open mind.** If they were there wouldn't be people going off to Greece stocking up on T3 pills. It's about 2 euros a packet in Greece and about quid 300 in the UK. **Patients going to Greece to self source medication; due to the cost crisis in the UK. Patient demand (threat; benefits versus costs of self sourcing remains despite CCG rules). Cost as primary barrier.** **How Endocrinologists feel** he one thing that's very common and what uh I can't work out why this has not been solved yet is the recent T3 crisis is difficult to take, we're seeing a lot of CCGs coming out with guidance to deny people T3 and that they're very inflexible and that makes me very angry and annoyed.

with mild hypothyroid changes GPs 'collude' with hopeful patients GPs not knowledgeable about thyroid GPs raise expectations 'They raise the expectations about we have found something physical and explained	your therapies, alternative therapies, complementary therapies, holistic approaches, that kind of thing, which I can't provide." in my experience, very few of these people have a diagnosable psychiatric disease. Sympathy, empathy, awareness of struggle to get to be seen Being supportive and non confrontational Listening, explaining Keeping the 'door open' (link to biological causes Need Endocrinology nurse to spend more time, educate address adherence, medication adjustments etc	Lack of tissue-level biomarker Reliance on symptoms which are like many other problems GPs overstretched, need quick answers for complex fatigue presentations Stress Lifestyle Medications Other autoimmune conditions Liver disease CFS/ME Diabetes Diet Sleep Anemia Work stress Somatic impact of stress Expectations of treatment (over expectation) for some group Normalisation of TSH to population level (not individual level) Open to low T3 in blood or 'tissue hypothyroidism' explanation	**How Endocrinologists feel** Very relaxed about it (happy to use personalised approach as experience has developed) Happy to sit on the fence and tell patients we do not know. Can be black and white an dogmatic or open More confident as experience in using additional treatments grows We have all struggled with these patients over te years (changed approach from dogma/gatekeeper/black and white to open minded and supportive and sees anecdotal evidence) **Engaging in changed practice** I am very open and honest, and tell people I used to be very negative. Now I sit on the fence and don't know, but say to the patients, "I'm	Um where I find it more challenging is when people go and their lives are still horrible **Clinician sad when cannot help patients (trials did not work or at edge of comfort zone with T3). Link to other clinician description of**

Appendix H: Collating Codes across data set (example excerpt)

Endocrinologists views about psychosocial and self-management interventions

Candidate theme 3: Psychosocial interventions/ embedded within practice

Interview 1a	Interview 2b	Interview 3c	Interview 4d	Interview 5e	Interview 6f
(not always well appreciated by patients, not experts in mental health/fatigue); Gp for depression or CFS investigation (not expert in these but suggest to patients) Patients not amenable to this suggestion. **Don't like being told 'all in head', threat** works well when embedded in practice; time, being clear about intensions and treatments, Give them time Tell them not alone, common problem Explain investigation Look for other conditions More than one consultation to investigate before	Belief in holistic approaches Need biopsychosocial approach and multi disciplinary approach (Dr, Endocrine nurse, health psychologist Those treated for mild hypothyroidism (problem is not the thyroid; some other cause); vague symptoms (more like chronic fatigue) may respond more to a holistic approach: support, promote approaches to help feel better (if not harmful) "What I think I can do is something we've discussed, is to help legitimise more holistic approaches when people are very biologically focused. I'd say, "Right, that's fine. I will deal with the biology, but I think it'll help you to have a wider approach to your therapies, alternative therapies, complementary therapies, holistic approaches, that kind of thing, which I can't provide." in my experience, very few of these people have a diagnosable psychiatric disease.	Endocrinologists have more time to educate patients (need 40/50 mins) about thyroid and hormones (link to BTF online education and patient information events; low uptake of physical events? online more utilised?). GPs have less time for exploration. Time is the key Form trust Collaboration Listening to what they are saying Understanding what they are going through looking for other causes (patients on board even if coming for T3). Education individualised exploratory approach (beyond individualised medicines approach) Expectations Action planning (how the next few months will work) Goal setting & action planning (for emotional/psychological management) Boundaries Validate; explain interplay between stress and body response, feeling like someone is listening its not what you say but the way that you say it Medication adherence: It's not what you say but how you say it	Partnership and structure (ensure trials are structured with ground rules, not 'willy nilly' link to interview 1 when says patients are like them in medical school; without experience/knowledge following tests rigidly and not having experience) Need to allow therapeutic trials before focus on psychosocial interventions think if they undergo a therapeutic trial and they feel better, then they're often more capable of dealing with other aspects of their life because they're not feeling quite so tired and run down. I've seen quite a number of patients, again it's only anecdotal who come in and then they bounce in having slumped in Managing risk, educating and informing, informed choice (clinician role) decision making (patient role). Not being the battleground unless there's black and white evidence in medical literature, in other words, studies, I think general well-being and how people feel is too nebulous a concept for commissioners and prescribers to swallow.	It's only when it becomes more challenging do they end up on our doorstep and usually by that point people are already in a healthy diet they've looked at ways to enhance the diet and exercise to manage the fatigue, they've seen lots of people already. I think we get a different group than the GP if that makes sense, but in our case we often find people have already been through most things. Lots of quackery out there and companies happy to make money from patients Good to have connection with other patients (link to interview 1 where other patients seen as problematic)	Patients with complex or unexplained symptoms need time, not quick fix prescriptions. There is a gap in NHS service and provision particularly for people with ongoing fatigue. There is a need for good health psychology service to help patients. Currently can only refer back to the GP (link to revolving door literature and heartsink quote from other interview Signposting role (British Thyroid Foundation is safe and trusted, evidence-based) . Referral to dietician, provide information on keeping physically active. Lack of support services in hospitals. Key monitoring role, and seeing patient more than once. Doctor patient interaction is important , time listening not fobbing patients off and 'rushing them out'. This is the success of 'rogue practitioners' they give patients time and make them feel listened to. (can I link to placebo effect from time and likeable doctors?) This may be as ffective as the T3 link to Peter Taylor, we cannot study the placebo or othr healing efects if medicine is unable to give time, and

discussion about T3 Clear about own views (do not endorse T3/ndt based on evidence) and concern for safety. Base on own knowledge and judgement (mr: pick up on a sense of personal responsibility; worry in some who rely on the evidence/guidelines - link to consultancy) I think it's a process of trying to impart good quality information about the condition and its treatment and to explain to them what you know my strategy is and offer them what I can offer them be clear I think in principle the more knowledge the better. I think it empowers people to know and understand so I'm always giving them time trying to explain and sort of educate as much as I can. Um (...)I think there are some risks in doing that if you take it to the extreme. Sometimes people are fixated about about	Sympathy, empathy, awareness of struggle to get to be seen Being supportive and non confrontational Listening, explaining Keeping the 'door open' (link to biological causes Try to discuss stressful life events: encourage them to work on that as well as the biological side (expectation): not enough time for holistic approach Patients do not want to engage in psychosocial aspects (want to focus on biological side). Link to interview 1; reluctance of patients (not well appreciated by patients) Education, scans, images Open collaboration enables disclosure, talk about risk An acknowledgment of listening is very important. Listening to all aspects and not belittling small ones yes Listening support is definitely helpful. More specific than that, I don't think I can narrow it down. Im tempted to just say to the patient, "For whatever you feel gives you more energy, so long as it's not going to be harmful, I would strongly be supportive of." Some people, they do a little bit of breathing	Agreement at the start (or never ending process) Manage expectations Collaborate Goal setting (3 month trial or never ending process) Listening, validation Not 'quick fix as GP Scaffolding; building up a picture of the illness with the patient (explanation, education, empathy) so do not build a brick wall. Level of care and understanding Empassioned conversation; listening to what they are saying; explaining that 't3 might not be the answer to all your problems' Educate about literature/RCT, unknown risks (combination treatment); open patients minds, hormones, how the body works, history of T4/T3 Lifestyle, caffeine sleep (vitamin deficiencies) All takes time Trust (in research and doctor) rather than online blog			drugs are too har to source and keep). This will add to the success of alternative and self sourced medicines and errode the effectiveness of medicine). Drs viewtheir role as safety and authority figures but find it hard to compete against those who want to profit from patients(sometimes rogue). Gap; need for professionals to look at lifestyle interventions. Need for GP support for patients with 'medically unexplained symptoms' t reduce referrals to hospital (revolving door) Need for GP education to understand impact of non-thyroid illness upon thyroid function test. Biopsychosocial approach needed (he calls it addressing somatic symptoms from life); lifestyle approach to health needed. However, many patients have their minds made up and focus on the thyroid only (fed by online info and difficulties at GP level). I don't have any graphical slides that I routinely use, but I often draw a thyroid gland on a piece of paper, and I draw pituitary, gland and I explain the feedback mechanism and how to interpret the function test, but there isn't a specific additional tool that I use. There isn't really any dedicated psychological support. Self managing dose can make things

the tests and one really difficult thing to it to transmit the thing to people is the significance of tiny changes, the um, er error in the measurements that is inherent. Sometimes they can over interpret the kind of data that comes in. But I think that's okay. It's a process. When I was a medical student, I did the same and you know with experience, you start to understand it better and to you know have a better insight into what it means. I think it is counterproductive to to prevent people from from going into this area. If that's what they want, if they want access to their results and you want them to understand them, then you've got to help them. I think that can turn and be a positive experience for them and and I think the empowerment is an important part of it but	exercise. I'm not sure that's a big thing. A few people engaging in other complementary therapies. Some people try meditation or mindfulness. I don't think I can identify one specific one. My rough shot at it is it is a more holistic listening and supportive approach. I think the answer is partial in the sense that what people think they benefit from is listening and an explanation and keeping the door open that there may be a biological explanation. Basically, that actually relaxes people a little bit to consider other things because it's like, "If you think I'm mad, I'm not going to have a conversation with you," but if I give them the legitimacy which I think is legitimate, that there may be a biological reason why they're not feeling well. That helps me engage more with other aspects. It gives me a bit more of a mandate todiscuss those things.				more complicated. I think there certainly is a degree of self-management like there is in any condition really and lifestyle is part of that. It's different from something like diabetes where you may have to self manage the dose that you gave. I think dose in a in a lot of these patients, they manage the doses themselves depending on how they feel, and that, if anything, makes it more difficult for us to assess what their status is because we're not actually really sure what they've been taking and how to interpret their results just in light of that.

again this is a general principle in medicine. Empowerment is fine, but I think if you've got to actually engage the patients in the process of trying to answer this question					
Interview 7g	Interview 8h	Interview 9i	Interview 10j	Interview 11k	Interview 12l
Time enables patients to build a rapport and develop trust think that's the huge gap what we have not only just with thyroid even with patients with any chronic conditions, diabetes as well. They should have that support actually, psychological support is	Communication skill: Difficult doctor patient communication when patients have pre-fixed beliefs Difficult conversation when science has ‘gaps’ (intra-cellular/tissue hypothyroidism); believes this is a valid point but ‘we’ve got no way of measuring that’	Information, education, understanding and trust and the key. Getting patients to understand and follow guidelines. All else is irrelevant and outside of clinician skill base. Patients need to be confident that you are an expert in the field. Time and communication skills underpin the process of building understanding and adherence.	Time, trust, communication, convince patients you are acting in their best interest; able to increase patient satisfaction even when you cannot give the patient the answer. Take pride in explaining to patients. Trust in relationships make unexplained symptoms easier to hear It's really important that they trust and believe that you	Psychosocial interventions: fear of bias on patient reported outcome measures due to wanting to keep the treatment. Problems with treatment skew results. Educate about risk; informed consent often they're very well informed patients. It tends to be a feature of patients and how I get that they're well informed. You're starting with a discussion where they've already got a	A lot of these patients, they complain of weight gain or difficulties maintaining weight. I know it sounds rather blunt, but generally, weight management comes down to a healthy diet and regular exercise, and I know that's much easier said than done link to BTF leaflet https://www.btf-thyroid.org/thyroid-and-weight-the-science However, also link to persistent symptoms (could be

Summaries/notes:

- Referrals to non-endocrine support not always well received by patients (depression, CFS seen as cause of symptoms). Focus on finding/fixing cause rather than maintaining health & wellbeing (not seen as in clinician role; don’t have will to change); distrust of doctors and the system
- Supportive care works best when embedded in practice
- Interview 9i Making causal relationships between psychological symptoms and thyroid hormone status is impossible. (link this Watt et al, 200– not trying to establish cause)
- Referral to non-endocrine support is particularly difficult for those who do not endorse personalised trials (‘heartsink’; stuck, revolving door) – especially when try to ‘diagnose ‘ I’m not an expert but compared to other who knows cfs criteria)
- Patients may have tried an extensive list of lifestyle related changes to feel better already (felt by those open to trials)
- For some, combination therapy restores ability to engage in healthy lifestyle behaviours- Key to rule out other conditions first

- For those who do not feel better on time limited trials, ‘other’ interventions seem more agreeable (however, cost, lack of experience and safety concerns – even in those with experience) as co aspects of health rather than alternative treatment for hypothyroidism
- Combination therapy to be a last resort due to issues with safety (some more relaxed with it; patients will stop if does not suit but cost makes this a problem). Some believe in the placebo effect (targeted trials required). To be structured and not adhoc (interview 4; also find interview 5; we used to do it on an ad hoc basis) – link to guidelines written by Dayan (no-one mentioned these), clear, boundaried, time limited (SMART goals – Dayan’s guidelines help this)
- Embedded Interventions (even interview 1 says works well when embedded in practice) : Create a table and put in **‘integrative approach vs medical model’;** ‘**psychosocial support within role vs psychosocial support not part of role or not enough time’** and **collaborative approach vs authoritarian approach**; … list them all but split into 2; 2 clear camps (one endorses integrative approaches, emotional support, personalised trials, open door approach; managing expectations, collaboration (vs collusion), scaffolding, links to more positive feel and patient reaction), one less open to these approaches, more inclined to refer externally for depression/CBT/CFS) due to feelings towards combination therapy.
- Providing knowledge and education (but not as passive recipients); need to engage them to find out what they want (1a)
- Empowerment as a burden on patients, patient choice undermining knowledge/experience of doctor as ‘expert’, worry about safety (personal responsibility of clinician)
- 11k (issues with PROMS) – patients Psychosocial interventions: fear of bias on patient reported outcome measures due to wanting to keep the treatment. Problems with treatment skew results. However; proms are good for working (problems with FS/ME/IAPT – recovery used as definition; whereas its about using everything we have to help you feel batter) - feel better and living well not necessarily recovery ; use cancer example.

Appendix I: Grouping codes to generate candidate themes

Endocrinologists views about hypothyroidism and its management:

- General attitude towards condition (1)
- Expectations/ Anticipated Changes to treatment (1)
- Anticipated changes to treatment (add to attitude towards condition?) (1)
- Trust/belief in scientific literature (1)
- Lack of funding and research
- Situation skews results
- Safety (Commercialisation of healthcare; medicalisation of life)

Endocrinologists views about hypothyroid patients

- Heterogeneity of thyroid subgroups (2) includes Unexplained illness; somatisation; biological/non-biological cause
- Reasons for persistent symptoms (2)
- Managing patient expectations (Thyroid might not be cause/T3 might not be the answer to all problems, (lack of definitive tests and personalised trials halts patients deciding for themselves)
- Cause of patient stress/distress (role of medicine in this) (2), leads on to psychosocial interventions section

Endocrinologists views about their role and self-identity as a doctor:

- How Endocrinologists feel (3)
- Experiences/competency of doctor (3)
- Personal belief-based approaches to practice (3)
- Open Vs closed door medicine / support for patient choice (3) Openness to trial personalised medicines (due to current research, patient expectations, from GP and online influences, knowledge and confidence of doctors)
- Link two above to training requirements (some use psychosocial skills others think its not in their skill set) (3)
- Role of doctor (Group of patients with vague symptoms being 'fobbed off' / failed (lack of time at GP level) or conned (bad doctors/social media) (3) Safety
- Self/social identity as doctor (collaborate vs collude with patients) provide expertise, safety. (3)
- Safety minefield (non human ration, rogue doctors (and other professionals/self sourcing) , patients influenced, marketing/commercialism/ fear of responsibility, unlicensed, unclear research and guidelines, personal capability, opportunity and motivation and responsibility, patient strong voice and personalised approach; lipservice to patient at the center). (3)
- Engaging in changed practice (sees results), need to have a will to change practice (3)
- Trust In doctor and patient **(**empowerment) (doctors are trained to have interpretive power but patients, social media and GP practices/CCGs are all trying to take this role;

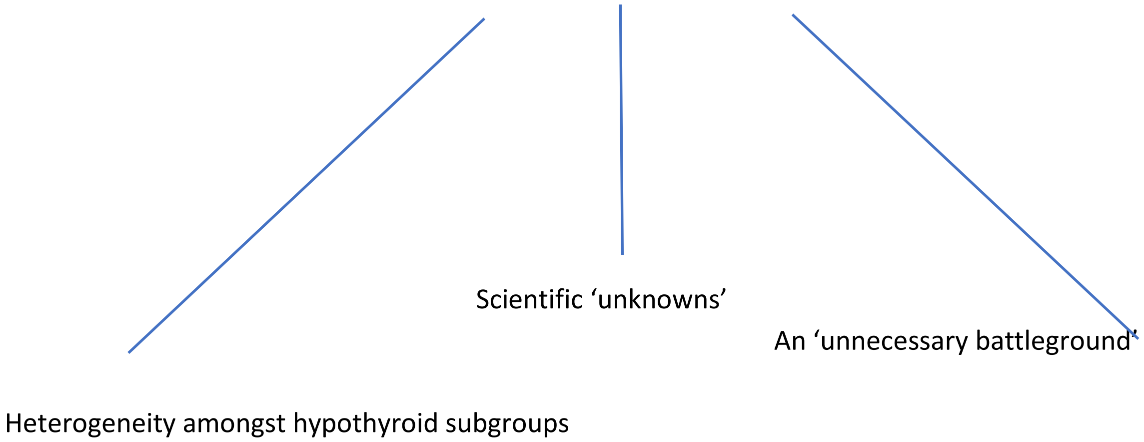
trust in training, expertise and knowledge of safety); trust as key psychosocial intervention? **(2/3/4)**

Endocrinologists views about non endocrine interventions:

- Psychosocial interventions (4)
- Trust
- Expectations (4)
- Referrals (charity dietician, GP, supportive care, lifestyle) (4)
- Need for a multidisciplinary approach? (4)
- Communication theory; persuade patients you are acting in their best interests (but problems in doing this; role of media, misinformation, ambiguous guidelines, problems with evidence base); its the way that you do it (time, trust) (4)

Appendix J: Developing candidate themes

Candidate theme 1: Endocrinologists views about hypothyroidism and its management



Subtheme 1: An unnecessary battleground has been created

- Hypothyroidism is mostly straightforward to detect and manage in the majority of patients, but difficulties are recognised to persist (differences in perception of group size are reported)
- Socio-political factors (unregulated cost of medicine) have eroded both doctors’ and patients’ sense of control: An unnecessary battleground has been created.

Sub theme 2: Heterogeneity amongst hypothyroid subgroups

- Different subgroups of patients with hypothyroidism exist/ Biological Psychological/sociological factors
- Patients with autoimmune thyroid disease have additional symptom burden due to inflammation/cytokines and should be monitored for additional autoimmune symptoms. This group requires a low treatment threshold for thyroid hormone replacement therapy (thyroid hormone therapy is less likely to alleviate autoimmune symptoms)
- Patients treated for thyroid cancer are likely to experience higher levels of symptom burden and psychosocial distress (e.g. rapid onset and treatment) and may struggle to adjust to T4 only therapy at lower doses after T3 and/or TSH suppression treatment. Over replacement may lead to psychological symptoms.
- Patients with no thyroid may be different to those with partial thyroid see 3 (link to female one; people feel ok for a while then do not)
- Individual differences may exist in response to treatment. People may have diagnosable hypothyroidism (not subclinical) and persistent hypothyroid symptoms (gaps in science,

‘we do not know’ tissue level and lack of biomarkers). Targeted trials are required for this group (but need to manage expectation) and to improve research quality. Difficult to separate this group and those in over diagnosed category).

- Some patients may have other overlooked problems not related to the thyroid (now includes reasons for persistent symptoms)
- Hypothyroidism requires lifelong monitoring and adjustment which can be sub optimally managed (or micromanaged) in primary care/ Patients sub optimally treated in primary care may improve with optimal treatment (NICE guidelines should support this; link to Dew study)
- Hypothyroidism symptoms are ambiguous and can lead to overdiagnosis and treatment/ Another group of patients with ‘medically unexplained symptoms’/ difficult to diagnose symptoms warrants more attention and support (at GP level; GPs often over diagnose as hypothyroid as a convenient hook for symptoms)… link to managing expectations; NHS embarrassing secret (can be exploited by the ‘wellness industry).
- Subjective norms (created from patient online communities) may impact upon on patient’s beliefs and motivation to comply with treatment / Difficult to study the 2 groups above if started on alternative therapies outside of NHS and without baseline data … need not to be dismissed by the NHS; keep open mind. Safer to work with them.
- Many reasons for persistent symptoms exist which need time to rule out before combination therapy should be started (list these, send to Endos?).

<u>Subtheme 3: Scientific ‘unknowns’ exist</u>

- Methodological limitations, guideline omissions, a lack of diagnostic biomarkers and regulated body-identical treatment preparations (T3/ndt), and prohibitive treatment costs are yet to be resolved)
- Up to 14 RCTs have explored different available treatments for replacing thyroid hormones
- Current studies are of weak quality (population-level studies/lack of targeted studies on appropriate population and incorrect dosing of treatments)
- New research is required with carefully targeted populations and accurate treatment dosing
- Without funding for improved research, no forward movement will occur (CCG power)
- Guidelines are tools, not rules
- Guidelines require specialist interpretive power
- New UK NICE guidelines give a ‘nod’ to patient with persistent symptoms and have ‘left the door open’ for personalised trials,

- A lack of guidance continues for administering personalised treatments (barrier for improved health outcomes) – link to Dayan study
- New UK NICE guidelines should reduce referrals to secondary care by optimising thyroid hormone replacement in primary care (guiding GPs)
- A lack of quality biomarkers or hypothyroidism (e.g. at tissue level) perpetuates the ‘ambiguity’ of symptoms
- Development of a synthetic long-lasting T3 preparation which mimics the body may address Endocrinologists’ safety concerns
- The current price of treatment is prohibitive to personalised trials; and research and development and perpetuates the battleground

Appendix K: Writing to develop overarching themes (example excerpt)

Additional Theme 1: Research/clinical and Socio-political contexts

Subtheme 1: Research and clinical context: 'Scientific 'unknowns' exist'

Participants described methodological limitations, a lack of diagnostic biomarkers and regulated body-identical thyroid hormone replacement preparations (T3/NTD) as scientific 'unknowns', compounded by prohibitive treatment costs and chronic underfunding to further knowledge and practice. In their accounts, they described that **u**p to 14 RCTs have explored different available treatments for replacing thyroid hormones:

Doctor A: " I'm not convinced by the arguments that the way that we replace thyroid hormones is suboptimal and the other ways of doing it will be better. I derive this opinion largely from the numerous randomised controlled trials looking at combined treatment with alone levothyroxine treatment, which have shown absolutely no difference I, I one has to accept that maybe there is a tiny, tiny sort of subgroup of people um by no means, is this anywhere like the 15%, but a really really subgroup that truly have a biological problem"

Doctor N: " We need to bear in mind that all the clinical trials haven't found the benefit, if you say. for the most, people can say that the randomised control trials and analyses have basically been negative for combination treatment.

Doctor O: " Certainly, there's not much good quality information that adding T3 to T4 and T3 to T4 treatment really makes a difference for most people."

Doctor P: " there have been trials of people given higher doses of Levothyroxine or given T3, and if you look at these trials, at how they conduct a trial, then they usually show that there's no benefit at all of additional therapy"

Doctor I: "I don't think there is adequate evidence or any evidence really to show benefits in prospective studies. The studies that I have seen and looked at in some detail suggest either no benefit or they are completely inconclusive and then the other thing is, although there's no data on potential side effects, that's something that concerns me, based on extensive studies in the basic science literature using animals" Doctor Q: " So, if thyroxine works well, just as well as T3 and we have all these experience and safety data on thyroxine, why not leave trying T3 and then make T3 the exception for those who do not clearly benefit"

Some participants, however, highlighted that the available studies to date are of weak quality (population-level studies and a lack of targeted trials with the appropriate patient population and incorrect dosing of treatments were identified as key flaws). These participants advocated for additional funding for new research with carefully targeted populations and accurate treatment dosing:

Doctor G: "Currently, that's where we are lacking. We do not have enough, well-designed studies, or the studies that have enough power to say that uh the additional treatments like T3 or NDT is useful."

Doctor *Q: "We've come some way and the kind of work we are doing is to actually see whether there is any link between things like genotype and wellbeing on thyroxine. If there's such a link. That would be the group in which we would need to do a randomised controlled trial.*

At population level is quite hit and miss. You could have people who have lots of other problems and you're just giving them T3 it won't work for them. You've got to try and find those patients who would have a physiological reason not to utilize T3, not to utilize T4, not to metabolize T4. That's hopefully what we'll achieve"

Doctor K: "The only sort of significant randomized control trial states there was no difference between T4 and the combination. Although with some trends towards some improvements perhaps in things like with combination therapy. The problem was it was a patient population who were fine on T4 alone. I don't think any of us would be advocating treating people with T4 alone-- I'm sorry, moving people who are fine on T4 alone to combination therapy. I think there is a need for a properly sized, randomized controlled trial combination treatment targeting those people who are still symptomatic on T4 alone, I think that will be very helpful."

Doctor C: "I think what they do show is that for the average hypothyroid patients T4 and T3 doesn't work but what we haven't got so far is the trial in this subset of patients. I'm not aware of any trials that have been conducted specifically in people who are unhappy with adequately with Levothyroxine. I don't think that exists. Secondly, I don't think we've got a trial in prospective trials rather than a subgroup trial in people with a specific Deiodinase polymorphism. There might be some truth in there that there might be a group of patients in which T3 might be beneficial but the problem at this point is we don't know who"

Appendix L: Supporting information from systematic review

1. PICO table

PICO	Included	Excluded
Population	Adults over 16 years including pregnant women. Diagnosed with thyroid diseases.	Babies and children Patients with thyroid cancer. Patients with ‘healthy’ status or with ‘other’ chronic illnesses (e.g. diabetes), tested for changes in thyroid function (e.g. in exercise studies) Studies conducted on animals.
Interventions	Psychological or social (including lifestyle) interventions. Single or multi-faceted interventions (including with biomedical primary but also with clear psychosocial outcomes) All study designs (RCTs and non-RCTs)	Diet and nutritional interventions (including supplements). Interventions to change behaviour of medical professionals. Physical outcomes but no link to psychosocial impact (e.g. specific aspects of cardiovascular health). Non-intervention studies.
Comparison	All comparisons included (standard care, non-psychosocial comparisons), as well as studies with no control groups.	
Outcome	All psychosocial outcomes. Quality of life and/or wellbeing. Definition widened to include coping and perceived fatigue. Outcomes assessed by quantitative outcome measures and by qualitative patient reports.	Psychosocial outcomes resulting from pharmacological or surgical therapy. Outcomes for other participant groups (e.g. carers, health professionals)
Other	All years of included journals. Studies with any length of follow up (including no follow up). Published and unpublished materials were considered for review.	Non-English language papers

3: Information sources, databases and other sources searched

The following databases were searched. No date restrictions were applied and at this stage, no language restrictions were applied.

1. CINHAL searched Nov 2016, search strategy developed and re-run January 2017 (2,411 results, 48 selected)
2. Medline searched December 2016, search strategy developed and re-run January 2017 (3039 results, 67 selected)
3. Psychinfo, Psycharticles, AMED searched together through EBESCO host January, 2017 (2577 results, 34 results selected)
4. Web of Science searched January, 2017 (2,741 results, 57 results selected)
5. Cochrane Library searched January, 2017 (42 results, 4 selected)
6. Science Direct searched January, 2017 (3,346 results, 14 selected)
7. The Cochrane Register of Controlled Trials (CENTRAL) searched January, 2017 (57 results, 4 selected)
8. Open Grey searched January, 2017 (1017 results, 6 selected)
9. ZETOC hand searched (12 results)
10. Google and google scholar were searched
11. Mail outs from internet peer and patient support groups were monitored for posted articles.
12. References from a number of popular self-help books were searched (and mail-outs from blogs joined).
13. Local information was obtained during a meeting with a member of the Bristol Clinical Commissioning group, and researchers contacted for information about current research in the area.
14. A meeting was held with a local specialist professor to discuss up to date publications.
15. Publishers from three universities were contacted about their work.
16. The British Thyroid Foundation were involved and were asked for relevant information and publication updates.

4: Search strategy

The search strategy for this review was adapted from a similar published review (Walklet et al, 2016) examining whether psychosocial interventions improve quality of life and wellbeing in adults with neuromuscular disorders. This paper was identified, and the author contacted for discussion. For the present review, the terms ‘multidisciplinary’, ‘nutritional’, ‘exercise’ and ‘pacing’ were also added to further capture behaviour change interventions.

Core search strategy:

1. (thyroid OR thyro* OR hyperthyro* OR hypothyro* or Graves or goiter OR T4 or TSH) : in any field

2. AND (psychosocial OR psychological OR biopsychosocial OR social OR "social support" OR "support group*" OR psychoeducation OR "peer support" OR counsel#ing OR "psychological therap*" OR psychotherapy OR psychodynamic OR "cognitive behavio#r*" OR cognitive OR behavio#r* OR CBT OR "self manag*" OR "self care" OR mindfulness OR "acceptance and commitment therapy" OR “telephone support” OR “nutritional support” OR supplementation OR diet OR exercise OR pacing OR “integrative team” OR “multidisciplinary team” OR “multidisciplinary education” OR placebo OR “functional approach” OR “functional medicine” OR “communication” OR EFT OR EMDR OR “trauma therapy” OR “motivational interviewing” OR “family therapy” Or “training” OR online OR skills): in any field

3. AND (“quality of life” OR "well being" OR "well-being" OR "wellbeing" OR "life satisfaction" OR "mental health" OR "psychological stress" OR anxiety OR depression OR pain OR fatigue OR inflammation OR adjustment OR "social participation" OR "positive psychology" OR "psychological adjustment" OR coping OR Cop* OR “body image”): in any field

Science direct changed to;

1. (thyroid OR hyperthyroidism OR hyperthyroid OR hypothyroid or hypothyroidism OR Graves or goiter OR T4 or TSH) : in any field

2. AND (psychosocial OR psychological OR biopsychosocial OR social OR "social support" OR "support group*" OR psychoeducation OR "peer support" OR counselling OR "psychological therapy" OR therapies OR psychotherapy OR psychodynamic OR "cognitive behaviour*" OR cognitive OR behaviour* OR CBT OR "self manage" OR management OR "self care" OR mindfulness OR "acceptance and commitment therapy" OR “telephone support” OR “nutritional support” OR supplementation OR diet OR exercise OR pacing OR “integrative team” OR “multidisciplinary team”

OR “multidisciplinary education” OR placebo OR “functional approach” OR “functional medicine” OR “communication” OR EFT OR EMDR OR “trauma therapy” OR “motivational interviewing” OR “family therapy” Or “training” OR online OR skills): in any field

3. AND (“quality of life” OR "well being" OR "well-being" OR "wellbeing" OR "life satisfaction" OR "mental health" OR "psychological stress" OR anxiety OR depression OR pain OR fatigue OR inflammation OR adjustment OR "social participation" OR "positive psychology" OR "psychological adjustment" OR coping OR “body image”): in any field

Appendix M: Poster presentation of findings

UWE Bristol | University of the West of England

Exploring Endocrinologists' views and experiences of psychosocial and self-management support for patients with hypothyroidism

Michelle Griffiths, Professional Doctorate in Health Psychology

Introduction

Hypothyroidism affects between 2% and 5% of the UK population. Reports suggest that up to 15% of patients report persistent symptoms despite standard treatment.

Recommendations exist for provision of psychosocial and self-management support for patients to address the demands of living with their condition and to develop the skills, knowledge, and experience to manage their health.

In this study, Endocrinologists were asked about the provision of support for patients with hypothyroidism in secondary care. Endocrinologists' views and experiences, and perceptions of the barriers and facilitators to the implementation of psychosocial and self-management models of care were explored.

Aim and Objectives

The aim of this research was to explore Endocrinologists' views and experiences of psychosocial and self-management support for patients with hypothyroidism.

The objectives of this research were:

- To examine Endocrinologists' views about the psychosocial and self-management support needs of patients living with hypothyroidism
- To examine Endocrinologists' experiences of providing psychosocial and self-management support within their own practice
- To examine whether Endocrinologists refer patients with hypothyroidism for additional psychosocial and self-management support
- To explore perceived barriers and facilitators to the implementation of psychosocial and self-management models of care

Method and Methodology

- Design: Qualitative with critical realist epistemology and contextualist ontology
- Participants: 18 Consultant Endocrinologists from the UK recruited via a snowballing sampling technique
- Data collection: Telephone interviews of 30-40 minutes
- Analysis: Reflexive Thematic Analysis with data interrogated semantically to provide experiential accounts.
- Quality, rigour and trustworthiness (over objectivity, reliability and generalisability)

Results: 'Walk with them'

People with hypothyroidism are heterogenous subgroups of patients, relying on lifelong medication to maintain hormonal health. They have diverse needs for psychosocial and self-management support from the point of diagnosis. Tailoring interventions to type of hypothyroidism may improve outcomes.

Patients with hypothyroidism are often activated and informed but are targeted by sources of misinformation and may develop rigid treatment beliefs. Attempts to provide psychosocial and self-management support may be met with resistance if perceived to devalue their illness experience.

Results: 'Embedded is best'

Endocrinologists described making time, listening and building trust as key elements of their role and a valuable start to the healing process. However, they report varied knowledge, skill, will, and confidence to incorporate psychosocial and self-management support in a structured or optimal way. Challenges to professional identity resulting from adopting new paradigms were described.

Difficulties in shifting the consultation focus towards wider determinants of health were reported and are perceived to be fuelled by the 'battleground' around access to LT3; patient perceptions of disregard, distrust and a lack of available service provision.

Endocrinologists were mostly supportive of patients using multiple approaches to improve their health, but attitudinal and behavioural differences exist towards use of LT3 and NDT with Endocrinologists feeling 'stuck in the middle' between personal responsibility for safety and risk and preventing 'polarisation' between dissatisfied patients and the healthcare system.

Endocrinologists report higher patient satisfaction when they embed a wide range of tools for investigation and treatment, even in cases where patients' symptoms are not fully resolved.

Results: 'Incorporate & collaborate'

Endocrinologists who view hypothyroidism as a chronic illness are more likely to involve patients as partners in their care. They advocate for the use of patient reported outcome measures to involve the patient voice to develop and evaluate treatments.

Results: 'Incorporate & collaborate'

Gaps in service provision to meet the diverse needs of patients with hypothyroidism were identified. These include regular reviews, education and expectation management from the point of diagnosis, and GP training to enable optimal treatment in primary care.

Improvements in primary care, along with collaboration with Patients, Endocrine Nurses, Health Psychologists, Pharmacists, Exercise Physiologists, embedded Researchers, and experts in the charitable sector are required to address these gaps through development and evaluation of interventions to meet the diverse needs of hypothyroid patient subgroups. These include patients with primary hypothyroidism; thyroid autoimmunity, survivors of thyroid cancer; and patients with complex multi-morbidity and medically unexplained symptoms.

Exploration of the feasibility of the application of existing multi-disciplinary, self-management models used in the treatment of other long-term conditions (e.g. diabetes, rheumatology and cancer) to patients with hypothyroidism. is required.

Results; We can't do this alone'

Funding and culture change are required to support doctors to place patients at the centre of their care.

- Address the cost of generic medicines in the UK (safety issues when patients have stable medication withdrawn or self-source from abroad; creation of feelings of helplessness, hopelessness and depression; perpetuates inequalities in healthcare delivery and reduces the professional 'toolbox')
- Invest in research to address scientific 'unknowns' and move the research conversation forward
- Create a system which empowers and activates patients, supports choice and addresses psychosocial needs
- Raise hypothyroidism up the political agenda.

Conclusions

Hypothyroidism includes heterogenous patient subgroups with diverse support needs, who require support from the point of diagnosis. Endocrinologists embed elements of support into their practice and report increased patient satisfaction but vary in will, skill and confidence to so. Multiple schemes of work are required to improve health outcomes.