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LIVING WITH AND BEYOND CUSHING'S DISEASE

Submitted to the New School of Psychotherapy and Counselling in conjunction with Middlesex University Psychology Department in partial fulfilment of the requirements for the Degree of Doctor of Existential Counselling Psychology and Psychotherapy by Professionals Studies.

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Declaration

This original piece of research has been conducted by Stephanie Yin Yeung Cho in partial fulfilment of the requirements of the New School of Psychotherapy and Counselling and the Psychology Department of Middlesex University for the Doctorate in Existential Counselling Psychology and Psychotherapy by Professional studies.

Ethical approval was granted on 26th April 2019 by the New School of Psychotherapy and Counselling and Middlesex University ethics board.

All content, unless otherwise stated and referenced, is the result of my own work and research. A list of referenced works can be found in the appendices.

Abstract

Cushing's disease is a rare endocrine condition caused by a benign hormone secreting tumour on the pituitary gland. By secreting Adrenocorticotropic hormone (ACTH), the tumour causes cortisol overproduction which leads to multiple physical and psychological symptoms including extreme weight gain, rounded face, skin thinning, depression and mood swings. Treatment for Cushing's disease often involves surgical removal of the tumour and medical therapy to lower cortisol; however, symptoms and sequelae of the condition persist. Literature on the subjective experience of Cushing's disease focuses on the impact of the condition on Quality of Life (QoL), and qualitative first-person research on lived experience is scarce.

The aim of this study was to shed light on the phenomenon of living with and beyond Cushing's disease through an existential-phenomenological exploration and heuristic analysis of the embodied experience beyond treatment. Six female participants including the researcher took part in unstructured interviews that explored the lived experience of Cushing's disease and framed these within the four dimensions of existence: physical, social, psychological, and spiritual. The findings of this heuristic inquiry demonstrate that Cushing's disease is a multidimensional phenomenon felt across all four layers of human experience. Themes also highlight the temporality of the illness experience and findings have been presented under a spatiotemporal framework integrating a temporal world interwoven with the four dimensions of existence. Implications of this research on medical and psychological practice are discussed and it is argued that subjective first-person accounts of illness should remain central to ensure holistic care. The research concludes that embedding existentially and phenomenologically informed psychological support within multidisciplinary services would serve towards ensuring that care for Cushing's disease patients addresses the totality of the illness experience rather than focusing solely on the functional impact of disease.

Keywords: Cushing’s disease, Cushing’s syndrome, Lived experience, Phenomenological, Heuristic, Existential, Embodiment, Chronic illness, Rare illness, Rare disease, Counselling psychology.

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1. Introduction

Cushing's disease is a rare endocrine condition in which the body produces excess levels of cortisol. Cortisol, sometimes referred to as the stress hormone, is an essential steroid hormone responsible for many important processes in the body including controlling metabolic and immune functions (Society of Endocrinology, n.d.-a). Cortisol levels naturally fluctuate throughout the day and in response to stress and daily activity demands. In the case of Cushing's disease, a benign tumour on the pituitary gland leads to consistent and abnormally high levels of cortisol. Excess cortisol is associated with physical symptoms such as rapid and excessive weight gain, high blood pressure, skin and bone thinning, and muscle weakness. Psychological symptoms such as mood swings, depression, and in some cases psychosis, are also well documented (Santos et al., 2019). Unfortunately, as with other rare conditions, the journey to Cushing's disease diagnosis may be long and arduous, involving unnecessary tests and even incorrect diagnoses, causing undue harm and suffering (Hoffman, 2014). If left untreated, Cushing's disease has a 50% mortality rate over five years, yet average time from first symptom to diagnosis is over three years (Rubinstein et al., 2020).

Treatment for Cushing's disease aims to reduce cortisol levels to within or below normal range, with first line treatment being pituitary surgery to remove the benign tumour. Surgical removal of the adrenal glands (that release cortisol in response to signals from the pituitary gland), radiotherapy to the pituitary, and medicines to reduce the effect of cortisol are all possible treatment options, but pituitary surgery is favoured and has a reported success rate of 60-80% (S. T. Sharma et al., 2015). However, pituitary surgery is not without risk and may lead to partial or complete hormone deficiencies including cortisol and other hormones regulated by the pituitary gland. Also known as the master gland, the pituitary is responsible for multiple vital processes in the body, consequently hormone deficiencies require medical management to ensure vital physical functions are preserved (Society of Endocrinology, n.d.-c). Despite the high reported success rates of surgical treatment, recurrence rates have also been reported up to 46% whereby recurrence means a return of excess cortisol levels following successful treatment (Huguet et al., 2015).

In 2006, the National Institute for Health and Care Excellence (NICE) produced guidance entitled *Improving outcomes for people with brain and other CNS tumours* (NICE, 2006). The guidelines highlight the psychological and social impact of Central Nervous System (CNS) tumours, including pituitary tumours, and recommend psychological assessment and support for both patients and their relatives and carers. Despite these guidelines and well documented psychological symptoms of Cushing's disease, patients continuously report unmet psychological and social care needs (Valassi et al., 2022).

1.1. Research framework

Cushing's disease has primarily been researched within a medical paradigm valuing objective measures and empirical findings. First-person subjective experiences of Cushing's disease are scarce in literature, meaning our understanding of the condition and its impact on those living with it is mediated by medical and psychological frameworks. Yet, illness is a first-person experience and understanding how Cushing's disease is experienced by those living with and beyond its diagnosis and treatment should be of central importance. Dr Harvey Cushing, the American neurosurgeon who first described Cushing's disease, was a proponent of adopting a psychosomatic approach to endocrinology by recognising the interaction of body and mind (Sonino, 2010). The phenomenological approach encourages an exploration of the experience of illness as lived, whilst existentialism provides philosophical grounding for such an exploration. Consequently, the theoretical framework and review of literature in this study has taken an existential-phenomenological stance with a focus on first-person lived experience to add depth and perspective to existing Cushing's disease literature. A strength of the existential-phenomenological framework is that it does not consider human experience in isolation but rather acknowledges that human beings cannot separate themselves from the world in which they are thrown (Heidegger, 2010). Understanding the lived experience of Cushing's disease is central to providing true patient-centred care and developing appropriate services and interventions.

1.2. Relationship to the area

At the age of 24 I was diagnosed with Cushing's disease. Like many other Cushing's and rare disease patients, the diagnosis came after many years of unexplained symptoms and being dismissed by medical professionals. In the end, I came across the diagnosis of Cushing's while googling my symptoms and managed to convince my GP to test for it with the support of a psychiatrist who had assessed me within an eating disorder (ED) service. I did not belong in the ED service as I did not have an eating disorder (just one of the examples of misdiagnosis I suffered), but I was grateful to finally be listened to. The formal diagnosis of Cushing's disease came after many tests and was just the first step in a life changing journey. I underwent multiple invasive procedures including five neurosurgeries, suffered a recurrence of Cushing's only a year after being told I was 'cured', and have been left with life-long medical dependency and no pituitary gland. At no point was my psychological wellbeing discussed or considered. I did not receive support in coming to terms with my diagnosis or to process its recurrence and I was not given an opportunity to discuss or explore the impact of going through medically induced menopause at the age of 29. I also found that despite being told I was in remission, I did not feel as though I was 'beyond' my Cushing's disease experience.

When I began working in psycho-oncology, I was reminded of the lack of psychological support I experienced throughout my Cushing's journey. I was on placement providing psychological support to those affected by cancer, helping patients, relatives, and carers come to terms with the challenges of being diagnosed, undergoing treatment, and the enduring effects of these. I started to reflect on the similarities between my experience and that of my clients and wondered why similar specialist services had not been set up to support patients with Cushing's disease or other rare conditions. However I had seen during my time as project officer for a rare disease charity that psychosocial support from statutory services was scarce for rare disease patients and their families who often relied on the support of patient organisations.

As I engaged in literature and reflected on my work in cancer and with health charities, I came to realise that despite the growing support for parity of mental health and physical health services, a mind-body divide is still the predominant paradigm in much of health research and practice. Medical conditions are mainly defined and understood in terms of their physical symptoms and in my experience, the psychological impact of health conditions is greatly underestimated. There is also little consideration for the long-term effect of treatment interventions and the priorities of the patient, which may differ from those of the medical professionals. Ultimately, there is very little consideration for patients' subjective experience of illness within the medical model.

Taking my experience of Cushing’s disease as a starting point, I became curious whether mine was an isolated one or if others felt a similar lack of psychological support. I wondered if perhaps others did not feel the need for such support and whether my focus on the lack of provision came from my professional interest in psychology/mental health. However, I soon learned through interactions with other Cushing’s and rare disease patients that unmet psychological needs are a common theme in rare conditions. Rather than approach the topic through established psychological or medical models of illness or distress, I wanted to start from the first-person perspective of experience and felt that an exploratory qualitative study would facilitate this.

1.3. Research Question

What is the experience of living with and beyond Cushing’s disease?

1.4. Research aims

This project aims to shed light on the experience of living with and beyond Cushing’s disease, through an exploration of the embodied patient experience. The hope is that this will enable anyone involved in the care of those with Cushing’s disease, to better understand their clients’ needs. It is also hoped that a richer and more rounded understanding of this experience will contribute towards better service provision and a greater awareness of the condition, and the issues patients face.

1.5. Outline of the study

Chapter 2 – Literature Review

The literature review is presented in a funnel structure and will begin by setting the scene for phenomenological understandings of illness and contrasting this approach to the medical conceptualisation of disease. Existential-phenomenological concepts of relevance to our understanding of illness as lived, notably embodiment and temporality, will also be presented. The four worlds’ model by van Deurzen (2015b) which provides a framework for exploring human experience will be outlined and existing literature on chronic and rare diseases provide a backdrop for the Cushing’s disease experience. A review of the literature on Cushing’s disease will highlight the predominance of quantitative studies and the focus of existing research on functional impact.

The few qualitative studies that have considered subjective lived experience of Cushing's will be presented, highlighting the gap this research aims to fill.

Chapter 3 – Methodology

The methodology chapter will outline the research methodology chosen to guide this study. Rationale for selecting heuristic inquiry will be put forward by stating the ontological, epistemological, and axiological positions that have informed this choice. Alternative approaches that were considered but ultimately rejected are presented followed by an outline of the process undertaken including steps taken to recruit, capture, and analyse the data. Transparent outlining of the method employed and how I have employed reflexivity throughout may serve to gauge reliability and validity of the study. Ethical considerations and limitations of the heuristic approach will also be explored.

Chapter 4 – Findings

The findings chapter is divided into two parts and will present both individual portraits that showcase idiosyncratic qualities of experience and keep the participant voice central, and a composite depiction of the phenomenon in the form of themes and sub-themes presented under spatiotemporal dimensions of existence: physical, social, psychological, spiritual, and temporal. The themes are supported by verbatim quotes and speak to the totality of the experience of living with and beyond Cushing's disease.

Chapter 5 – Discussion

Following the findings chapter is the discussion chapter which will place the findings within the previously reviewed literature and introduce further literature to contextualise novel findings. A discussion of the implications of this research will follow and limitations of the study will also be discussed. A reflexive discussion on the research process will be presented in keeping with a heuristic approach. Finally, dissemination plans along with suggestions for future research will highlight the continuing contribution this study aims to make.

Chapter 6 – Conclusion

The final chapter will summarise and bring together salient points from the research.

2. Literature review

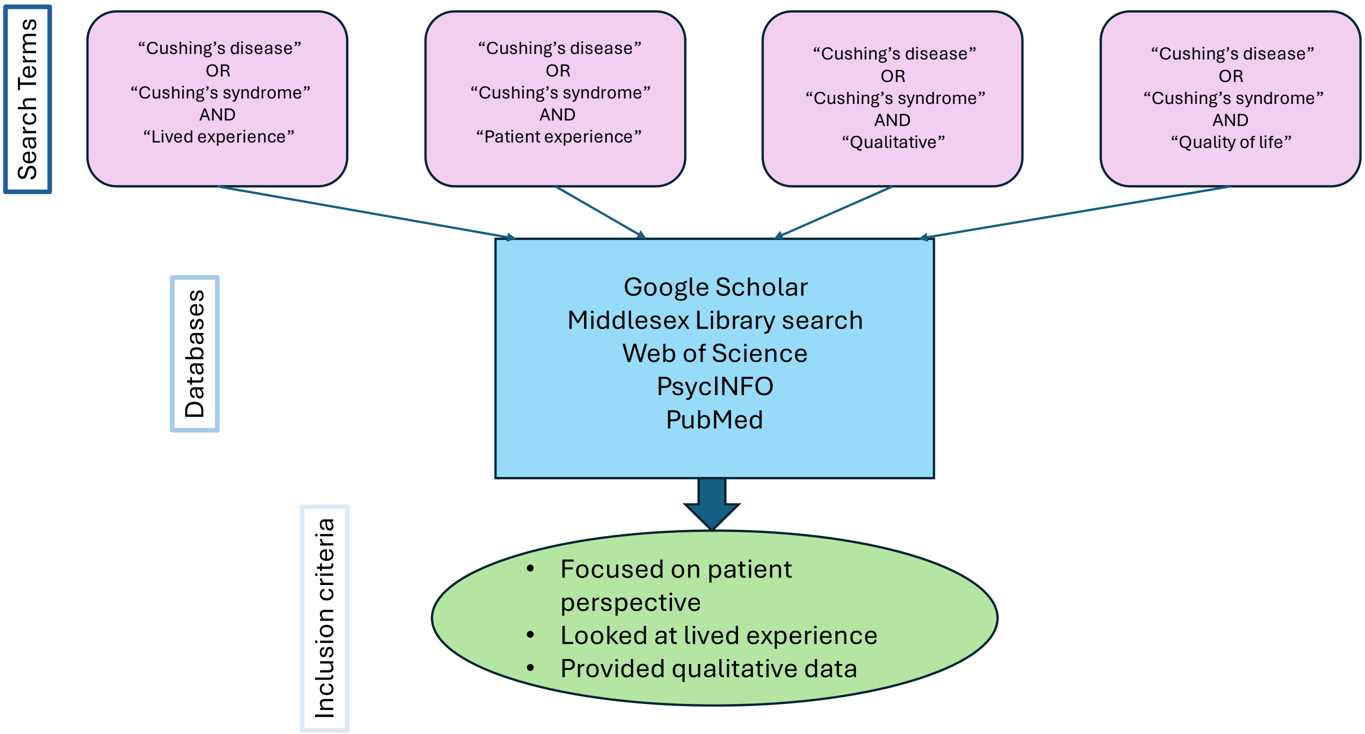
Cushing's syndrome (CS) is a condition caused by chronic excess cortisol in the body. Often due to long-term steroid use, CS can also occur when a hormone releasing tumour on the pituitary gland causes overproduction of cortisol, leading to life-threatening complications. In this case, the condition is referred to as Cushing's disease (CD). CD is a rare endocrine condition with only 60-120 new cases reported each year in the UK (Society of Endocrinology, n.d.-b). Clinical definitions of CD list both psychological and physical symptoms including weight gain/obesity, muscle weakness, fatigue, skin thinning, depression, and mood swings (Society of Endocrinology, n.d.-b).

Like in other rare conditions, scientific research, and literature on the patient experience in CD is limited. I begin by outlining how the literature search was conducted, highlighting the lack of research data on the lived experience of CD. The literature review has been presented in a funnel structure beginning by providing an overview of the emerging literature on the phenomenology of illness and the experience of being a patient from the first-person perspective, setting the scene for embodied and multidimensional understandings of illness. I consider the literature on chronic (section 2.7.) and rare conditions (section 2.8.) before reviewing the available literature on Cushing's disease and Cushing's syndrome. There are many studies concerned with the physical and psychological symptoms of the condition and the topic of quality of life, with very little qualitative data. As such, this is reflected in the Cushing's literature review, which is dominated by quantitative studies, however, I attempt to highlight the subjective patient experience. I present findings of qualitative studies in Cushing's and bring to light the gap this research aims to fill. As the study aims to look at the experience of living with and beyond CD, studies capturing the post-treatment experience are also presented, including studies on the experience of secondary adrenal insufficiency (a frequent consequence of CD treatment).

2.1. Search protocol

I began my literature search by entering the key words "Cushing's disease" AND "lived experience" into Google scholar which produced 34 results, with only one doctoral thesis of relevance (King, 2003). The same search using the Middlesex library search produced no results. I decided to run the searches again using "Cushing's disease" AND "patient experience" which produced 89 results in Google scholar, including one qualitative paper (Graffigna et al., 2020) and one quality of life study (Webb et al., 2021) of relevance. Most results were medical papers that did not cover the lived experience of patients. I then conducted the search using Middlesex library search, which produced only 7 results, all unsuitable including a quality of life paper focusing on measuring quality of life to compare outcomes between two surgical interventions. I proceeded to run several searches using Web of Science, PsycINFO and PubMed with the following key words: “Cushing’s disease” OR “Cushing’s syndrome” AND “patient experience”; “lived experience”; “qualitative”; “quality of life”. I decided to use both Cushing’s disease and Cushing’s syndrome as search terms to broaden my results since studies do not always distinguish between the various aetiologies of Cushing’s.

Figure 1 *- Search protocol flowchart*



Searches including “quality of life” produced the largest number of results and I have attempted to provide a broad overview of these studies, however including all quality of life literature is beyond the scope of this project which focuses on qualitative lived experience. In addition to running keyword searches, I also used the snowball method to identify other potential resources.

To gain a broader understanding of the literature on the lived experience of illness, I found it helpful to consider texts which explore the patient experience through first-person accounts (see Frank, 2002; Toombs, 1992a). These texts speak to the existential dimension of illness, whilst connecting personal accounts to existential-phenomenological theory, particularly the works of S. Kay Toombs (Toombs, 1988, 1990, 1992a, 1992b). Her book *The meaning of illness. A phenomenological account of the different perspectives of physician and patient* (Toombs, 1992b), spurred me to reflect on the body as conceptualised in biomedical thought, versus an existential-phenomenological conceptualisation of body and illness. I found myself returning to the original writings of Merleau-Ponty (1948/2008) and Heidegger (1987/2001, 1953/2010), whilst also engaging in contemporary views on the phenomenology of illness, such as the works by K. Aho (J. Aho & Aho, 2008; K. Aho, 2018), Carel (2011, 2012, 2016, 2021), Leder (1990, 1992, 2016, 2022), and Svenaeus (2000, 2009, 2011, 2013, 2019).

2.2. The medical model

To situate lived experience and first-person accounts of illness within medical research, I begin by outlining the 'traditional' medical model. Western medicine has evolved out of a strong positivist tradition in science. The paradigm of medicine is one of realism, positivism, and materialism (Wilson, 2000). At the core of medical practice is a reductionist conceptualisation of body-as-machine, whereby doctors employ technology to examine the body and its mechanistic internal functioning (Leder, 1992). First-person accounts are seen as impeding in medical assessment and the focus of the medical professional is on biological dysfunction, the material body, and objective observable 'facts' (K. Aho, 2014). Ultimately, the traditional medical model is one of *disease*, rooted in anatomicopathological understandings (Baron, 1985).

Although human experience can indeed be quantified and reduced to physical and chemical processes with causal relationships, these explications are insufficient in illuminating human behaviour and phenomena (Boss, 1983). Medical practice has sought to address some of the issues of the traditional biomedical model, most significantly with the introduction of the biopsychosocial model by Engel (1978). The biopsychosocial model based on general systems theory is a framework that suggests health and disease are not just about our biology, but also about our thoughts, feelings, behaviours, relationships, and the world around us. "the biopsychosocial model dispenses with the scientifically archaic principles of dualism and reductionism and replaces the simple cause-and-effect explanations of linear causality with reciprocal causal models." (Engel, 1978, p. 175). There have been other movements which have sought to tackle medicine's reductionist tendencies including the holistic movement, patient-centred care, and narrative-based medicine (Zaharias, 2018). Multidisciplinary teams have now become best practice in many specialities of medical care including palliative and oncology (National Institute for Health and Care Excellence (NICE), 2004). By drawing on various schools of thought and adopting interdisciplinary approaches, these movements have edged medicine towards a more holistic paradigm whereby the General Medical Council now advises that:

> Newly qualified doctors must be able to work collaboratively with patients, their relatives, carers or other advocates to make clinical judgements and decisions based on a holistic assessment of the patient and their needs, priorities and concerns, and appreciating the importance of the links between pathophysiological, psychological, spiritual, religious, social and cultural factors for each individual. (General Medical Council (GMC), 2020, p. 16)

An emerging view in the philosophy of medicine is the phenomenology of illness. Inspired by the philosophies of Husserl, Heidegger, Sartre, and Merleau-Ponty, this field of study has focused on the first-person perspective and lived experience of *illness* (Svenaeus, 2019). I distinguish between the terms disease and illness, where *disease* refers to organic pathology defined in objective physiological terms, and *illness* encompasses the subjective lived experience of suffering (Leder, 2016). The lived experience of illness encompasses social, ethical, and existential dimensions, and contrary to the dominant scientific medical view, is not secondary to objective disease, but rather is a primary fundamental phenomenon of human experience (Carel, 2016). According to Baron (1985) "phenomenology attempts to examine the ground on which natural science walks. By taking seriously questions about the world as experience (rather than taking scientific description to be the world of all that is)" (p.608).

2.3. The body in disease and illness

One of the key contributions of phenomenology to our understanding of illness is the concept of *embodiment*, which challenges the Cartesian principle of mind-body dualism. Embodiment posits that it is through my body that I experience and engage in (and with) the world, as being-in-the-world

(Heidegger, 1953/2010). Merleau-Ponty (1948/2008) describes being-in-the-world as also being-in-the-body. I situate and orient myself through my body in the interplay between body, perception, and world. How the world presents itself to me is mediated by my body intersubjectivity therefore there cannot be a separation between self and world (Russon & Jacobson, 2018). The concept of embodiment succeeds where the traditional paradigm of medicine fails by providing a framework to understand and explore lived experience (Baron, 1992). Merleau-Ponty's (1948/2008) exploration of the body-subject also provides insight into the ways in which individuals develop understanding, self-acceptance, and shape their identity through embodied experiences. Conversely, the relationship between self and body in medicine often supposes a separation in which the body is seen as "servant of the self", reifying the concept of body-as-machine (Baron, 1992, p.40).

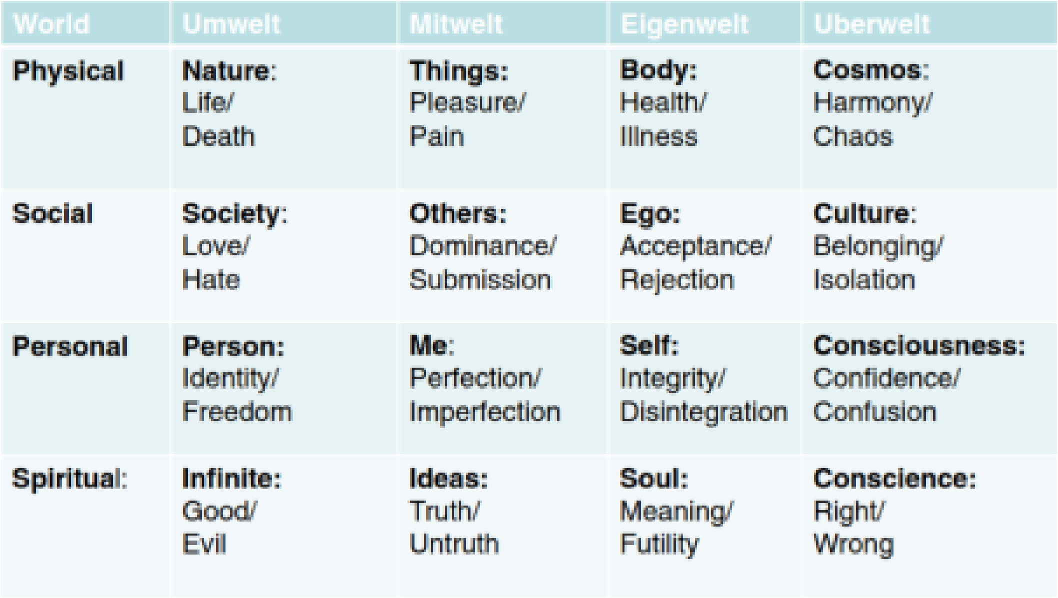
Phenomenology distinguishes between the *Körper* and *Leib* (Husserl, 1931). The Körper is our physiological being that can be scientifically investigated, whereas the Leib is our lived experience of this physiological being. The distinction between Körper and Leib is key to our understanding of the difference between disease and illness (J. Aho & Aho, 2008). Medicine deals with the *Körper* - the corporeal objective body, the body-as-machine, whereas illness is an experience of the *Leib* – the lived subjective body (Heidegger, 1987/2001). Focus on the Körper has led medicine to reduce the patient's lived experience of suffering and illness, to functional and mechanistic descriptions of disease (Leder, 1992). The Leib is relational, intentional, and full of implicit meaning; therefore, the embodied experience of illness is necessarily relational, intentional, and full of implicit meaning.

2.4. Being in the world

Through our embodied engagement in the world, we relate to others and develop our sense of self and beliefs about the world. Human experience is consequently subjective, contextual, and situational (van Deurzen, 2010). My experience of the world is also inevitably uniquely mine as I experience it differently from others. As an alternative to the medical model and based on the concept of being-in-the-world, Binswanger developed a relational framework to describe human experience (van Deurzen & Arnold-Baker, 2005). His three-world model of *Umwelt*, *Mitwelt* and *Eigenwelt* was later expanded by van Deurzen to include the fourth dimension of *Überwelt* (van Deurzen & Kenward, 2005). The four dimensions of existence are interrelated and represent the ontological givens of existence, providing a framework for the exploration of experience (van Deurzen, 2010). The physical world (Umwelt) is the dimension of the biological and encompasses our relationship towards the natural world. The social world (Mitwelt) is the dimension of relationships with others, which are necessarily embedded in social, cultural, and political contexts. The psychological world (Eigenwelt) is the personal dimension of thoughts, feelings, identity, and selfhood. The spiritual world (Überwelt) is the dimension of meaning, values, and beliefs. Medicine's disease model can be said to focus on the physical dimension, whereas illness is a multidimensional experience.

Van Deurzen (2015b) suggests there are tensions and dilemmas that exist in each dimension (see Figure 2); however, these tensions should not be viewed as polarities, but rather represent the paradoxical nature of human experience. As van Deurzen (2015b) states: "The paradoxical nature of existence is that only to the extent that we are willing and able to deal with one side of the equation can we manage the other side successfully as well." (p.78).

Figure 2 *- Tensions and paradoxes of existence*



World	Umwelt	Mitwelt	Eigenwelt	Uberwelt
Physical	**Nature**: Life/ Death	**Things:** Pleasure/ Pain	**Body:** Health/ Illness	**Cosmos**: Harmony/ Chaos
Social	**Society**: Love/ Hate	**Others:** Dominance/ Submission	**Ego:** Acceptance/ Rejection	**Culture**: Belonging/ Isolation
Personal	**Person:** Identity/ Freedom	**Me**: Perfection/ Imperfection	**Self:** Integrity/ Disintegration	**Consciousness:** Confidence/ Confusion
Spiritual:	**Infinite:** Good/ Evil	**Ideas:** Truth/ Untruth	**Soul:** Meaning/ Futility	**Conscience:** Right/ Wrong

(van Deurzen, 2015b, p.79)

By exploring first-person accounts of illness through a multidimensional framework, we can examine and plot how the experience of illness is expressed in our being-in-the-world and the tensions and paradoxes within it.

2.5. The experience of illness

The patient experience is necessarily an embodied experience of illness, as life is lived in the body (Merleau-Ponty, 1948/2008). Sartre (1943) considers the experience of illness a confrontation with the limitations and contingencies of the human body. He asserts that illness can disrupt one's sense of freedom, autonomy, and the ability to pursue personal projects, highlighting the existential challenges it poses (Sartre, 1943). Illness disrupts our usual ways of participating in the world and frustrates our intentions, we become aware of our body-as-object and the body becomes “uncanny”; yet we cannot escape this “impaired embodiment” (Toombs, 1992a, p. 135). The uncanny body is a body that no longer feels familiar and reveals what was previously taken-for-granted (Madeira et al., 2020).

An intertwining of body, self, and world occurs in illness as the uncanny body leads to uncanny situatedness and unhomelike being-in-the-world (Finlay, 2003). Leder (2016) refers to this as being in exile from the body, social world, and cosmos. Exile from the body represents our body feeling unhomelike which is often heightened by medical treatments when the body is further objectified and alienated. Exile from the social represents how relationships are altered. Yalom (1980) acknowledges that illness can lead to a sense of isolation and alienation. The experience of illness can be deeply personal, and individuals may feel disconnected from others who cannot fully understand their pain or the challenges they face. This isolation can intensify existential anxieties and feelings of loneliness (Yalom, 1980). Illness can exile us from the social world through stigma, but we may also self-exile through shame. Symptoms of illness are interpreted through internal frames of reference that include personal meaning, but also cultural and ethnic interpretations. How we present our ‘self’ to others is embedded in our bodily patterns such as how we speak, walk, and gesture. When illness leads to body changes that do not match up to cultural ideals and therefore project a negative body image, these can be particularly difficult to come to terms with as they are interpreted as negative projections of self (Toombs, 1992b).

A diagnosis of illness can lead to feelings of despair and meaninglessness and forces us to confront our mortality in a very direct and existentially demanding way (Carel, 2016). Exile from the cosmos, therefore, represents the shattering of our beliefs in an ordered universe, as illness can strengthen spiritual beliefs but also challenge beliefs about self, others, and the world (Ownsworth & Nash, 2015). It is an existential crisis which threatens identity and personal values about what is meaningful in life (Toombs, 1992b). Fundamentally, illness impacts the totality of our experience, it is “a complete form of existence” (Merleau-Ponty, 1948/2008, p. 110).

However, according to Yalom (1980), illness can also serve as a catalyst for personal growth and self-reflection. He highlights the importance of finding meaning in suffering and using it as an opportunity to re-evaluate one's values, relationships, and priorities (Yalom, 1980). Frankl (2008) also emphasises the importance of finding meaning and purpose in the face of adversity and illness to overcome and even transcend this suffering. Jaspers (1954) introduced the concept of limit situations to describe experiences that confront individuals with the fundamental boundaries of human existence. Illness, along with other limit situations like death, suffering, and guilt, forces individuals to confront the limitations of their existence and grapple with questions of meaning, mortality, and the human condition. For Jaspers, limit situations like illness serve as opportunities for existential reflection and self-awareness. They compel individuals to confront the ultimate concerns of existence and to reassess their values, priorities, and beliefs in light of their experiences. Illness can therefore be understood as a limit situation that prompts individuals to confront the boundaries of their existence and to seek meaning and purpose in the face of adversity.

2.6. Time

In addition to being an embodied experience, illness is a temporal one. The world we experience is temporal and we are beings in time, therefore lived experience is inescapably temporal, however, our awareness of time is often concealed from us. Temporality can be split into objective and subjective time. *Objective time* is the time of clocks and calendars whereas *subjective time* is my experience of time as perceived, remembered, and constructed (Brough, 2001). This distinction between objective and subjective time can be likened to the distinction between Körper and Leib. Indeed, temporality and embodiment are parallel structures, whereby subjective time is an implicit function of the Leib (Fuchs, 2005). Consequently, lived experience of illness cannot be gauged in explicit and objective measures of time as it is experienced as subjective temporal disruption (Toombs, 1992b). Illness alters and ruptures our awareness of time as past and future now appear alien with a “strange quality of being, simultaneously mine and yet no longer mine” (Svenaeus, 2011, p. 339). Ordinarily, human experience is future focused as we engage in activities consistent with our desired goals (Heidegger, 1953/2010), however illness narrows this focus as certain goals become unachievable (Leder, 2022).

2.7. The chronic illness experience

Temporality is a particularly salient concept in chronic illness. Compared to acute illnesses that are transient, chronic illness endures and brings social and existential issues to the fore - issues in everyday experiences, meaning, morality and identity. It leads to a constant reappraisal of self and way of living (Charmaz, 1991). Suffering in acute illness is contained, however in chronic conditions, the sense of suffering may feel interminable (Leder & Jacobson, 2014). As Toombs (1993) highlights:

> In chronic illness the future assumes an inherently problematic character. One can never be certain, from one day to the next, as to the extent of one’s physical capabilities. Thus, one is effectively confined to the present preoccupied with the dictates of the here and now. (p.225).

The ‘uncanny’ experience of alienation in illness is paradoxical – I *am* my body and cannot ignore my (impaired) embodiment, yet my body feels ‘other-than-me’ (Toombs, 1992b). This alienation is particularly profound in chronic conditions due to the enduring quality of illness which leads to an inescapable impaired embodiment. Living with a chronic condition is “*living* a [specifically] disordered existence”, not just *having* a disorder (Toombs, 1992b, p. 81, my emphasis). Toombs (1993) speaks of *metamorphosis* that occurs in chronic illness whereby the healthy body morphs to the diseased body and disease becomes a fundamental aspect of self, with no possibility of reversion.

First-person accounts of chronic illness have also shown us that chronic patients often experience stigma which can lead to feelings of shame and guilt, and to limit stigma chronically ill people must mediate disclosure of their condition (Joachim & Acorn, 2000). Deciding whether to conceal or reveal can pose a real ethical dilemma as cultural and social norms towards illness mean disclosure could lead to revealing something potentially discrediting. Goffman (1963) used the term ‘discrediting’ to refer to the process by which an individual's social identity or status is undermined or invalidated in the eyes of others, often leading to a loss of social standing or respect within a particular community or society. In professional environments, chronically ill persons may experience strong repercussions as disclosing a health condition may raise concerns about how it could impact job performance or career advancement. There may be fears of discrimination or being treated differently by employers or colleagues.

Disclosing illness can also impact dynamics in relationships with family and friends who may start to treat you differently or may even leave. Revealing illness therefore means holding one's own feelings about disclosure whilst managing the feelings of others in response to being told.

> Thus, the dilemmas of disclosing turn on control – control of identity, control over information, control over emotional response, and control over one's life. Hence, avoiding disclosure entirely, maintaining distance, metering disclosures, censoring information, and pacing disclosures all become ways of preserving control. (Charmaz, 1991, p.110)

Relationships with healthcare professionals can also be strained because chronic patients often become experts in their condition, which challenges the medical ideal of passive patients (Charmaz, 2000). Finally, expectations about the transformative power of illness and the need to confront mortality can be overwhelming (Piemonte & Ramsey, 2018).

2.8. The rare illness experience

There is no agreed definition as to what constitutes a rare disease as different countries use different thresholds; however, a common definition is that it affects a small number of people and raises specific issues due to its rarity. In Europe, a rare condition is one that affects less than 1 in every 2000 people (Orphanet, 2012). Unique issues of rare diseases include difficulty accessing care and support, lack of medical knowledge, lack of public awareness, but also increased psychological, social, and economical vulnerability (Orphanet, 2012), and many rare conditions are chronic. As there are over 7000 rare diseases, it is estimated that around 1 in 17 people will be affected by a rare disease, which amounts to around 3.5 million people in the UK (Rare Disease UK, n.d.), and it is suggested that challenges such as unmet medical and social needs are experienced by rare disease patients globally (Chung et al., 2022).

A report by Rare Disease UK (2018) found that low awareness of rare conditions could be linked to delayed diagnosis and lack of attentiveness to the emotional impact of having a rare condition. In their survey of 1,350 patients and 571 carers, they identified high levels of worry/anxiety (95%), feeling stressed (93%), feeling low (90%), emotional exhaustion (88%), and feeling at breaking point (70%). In a systematic review of the qualitative literature on living with a rare disorder, von der Lippe, Diesen and Feragen (2017) identified three main themes consistently reported: 1) Consequences of living with a rare disorder, 2) Social aspects of living with a rare disorder, and 3) Experiences with the health care system. Living with a rare disorder includes the physical and psychological consequences but also encompasses the constraints and limitations these place on patients, and the coping strategies utilised. Social aspects of living with a rare disorder touch on themes of disclosure, stigma, comparing similarity and difference, and lack of social support. Experiences with the health care system highlight the challenges of lack of knowledge, the quality of interactions with health professionals, and the need to become expert patients (von der Lippe et al., 2017). Each theme points to the unique and qualitatively different aspects of living with a condition that is not only chronic, but also rare.

Findings from these studies suggest that the lived experience of rare illness heightens the sense of exile from the body, social world, and cosmos (as previously outlined in section 2.5.). Exile from the body is intensified by the experience of rare disease patients often undergoing experimental and invasive treatments. Exile from the social world and the sense of isolation and alienation that comes with illness is tenfold in rare conditions where patients often do not meet others with the same condition, and there are no internal or external frames of reference for the condition as opposed to more common diseases such as cancer that have a ‘public story’ (Pinnock et al., 2011). Finally, although the spiritual dimension has not been specifically reported on in these studies, it is reasonable to conclude that exile from the cosmos is amplified in the rare illness experience because of the high degree of uncertainty due to lack of knowledge, and the sense of meaninglessness a rare diagnosis might engender.

Further studies on the experience of living with a rare disease would speak to the idiosyncratic quality of a particular condition and to the broader existential predicaments of rare illness as lived.

2.9. Cushing’s disease

The following section presents literature on Cushing’s disease by outlining the condition, its symptoms, presentation, and treatment, and research on the patient experience that has been undertaken to date. Most studies on the patient experience are quality of life studies, however six qualitative studies are also presented, four of which focus specifically on Cushing’s whilst the other two report more broadly on pituitary tumours including Cushing’s. Literature on secondary adrenal insufficiency is also presented as it is a common consequence of Cushing’s treatment.

2.9.1 The role of cortisol

Cortisol is a vital naturally occurring hormone in humans and animals alike. Also known as the ‘stress hormone’, it is most commonly associated with the fight or flight response since it is released by the adrenal glands in reaction to stress. However, cortisol serves many functions including regulating metabolism and blood pressure, controlling memory formation, aiding in the development of the foetus, and acting as an anti-inflammatory (Society of Endocrinology, n.d.-a).

Although cortisol is necessary for life, too much of it can be extremely problematic. Chronic excess cortisol leads to symptoms such as extreme weight gain, high blood pressure, muscle weakness, thin bones, poor wound healing, and thin skin that bruises easily. It can also lead to psychological problems such as depression, anxiety, and mood swings (Newell-Price et al., 2006). This collection of symptoms due to excess cortisol is referred to as **Cushing’s syndrome (CS)** and individuals may also be described as looking Cushingoid (see Figure 4). CS usually develops due to exogenous factors such as long-term use of anti-inflammatory corticosteroid medication in the treatment of common conditions like asthma and eczema. In cases where individuals present with Cushingoid symptoms through no obvious external cause, investigations take place to pinpoint the location of the endogenous source, which in around 80% of cases is a benign adrenocorticotropic hormone (ACTH)-secreting tumour on the pituitary gland (Newell-Price et al., 2006). The pituitary gland controls cortisol levels throughout the day in response to stress, both physical and psychological (Society of Endocrinology, n.d.-a). When a tumour on the pituitary gland leads to excess cortisol secretion or stimulation, the condition is referred to as **Cushing’s disease (CD)**.

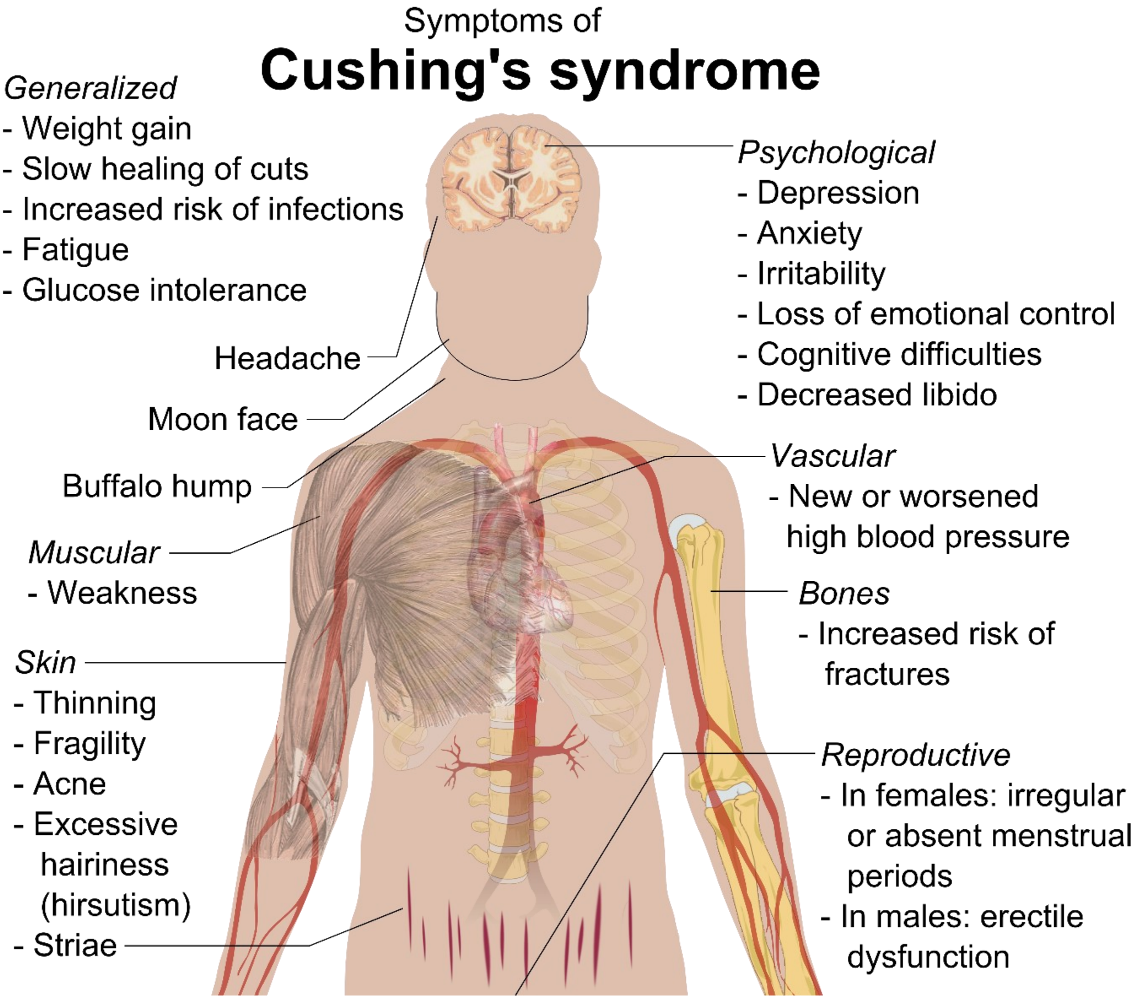
CD is very rare, with only 0.7 – 2.4 new cases per million diagnosed each year. It is also a very serious condition that carries with it an increased mortality rate five times higher than the general population (Newell-Price et al., 2006). Patients with CD are also at an increased suicide risk due to higher rates of major depression (Pivonello et al., 2017). CD tends to affect women more than men with a reported ratio of 3.5 to 1, and it is suggested that clinical presentations differ across genders (Newell-Price et al., 2006). Giraldi, Moro and Cavagnini (2003) found that men tended to present with more severe clinical symptoms and had worse prognosis after surgery, whilst a study by Milian and colleagues (2014) found that women experienced more severe mood and depressive symptoms than men, even when female prevalence was considered. Kreitschmann-Andermahr and colleagues (2015) also identified gender differences in the diagnostic process whereby significantly more women reported having observed the onset of symptoms themselves, whereas men were more likely to have CD symptoms recognised by their physician.

The literature presented below includes both CD and CS studies as the two are often grouped. Although CD only refers to pituitary-dependent Cushing's, CS refers to Cushing's from all aetiologies (including pituitary) and can therefore be considered an umbrella term.

2.9.2. Symptoms, presentation, and treatment

The impact of CD is multidimensional, it causes physical, functional, social, and psychological impairments (see Figure 3).

Figure 3 - Symptoms of Cushing's syndrome

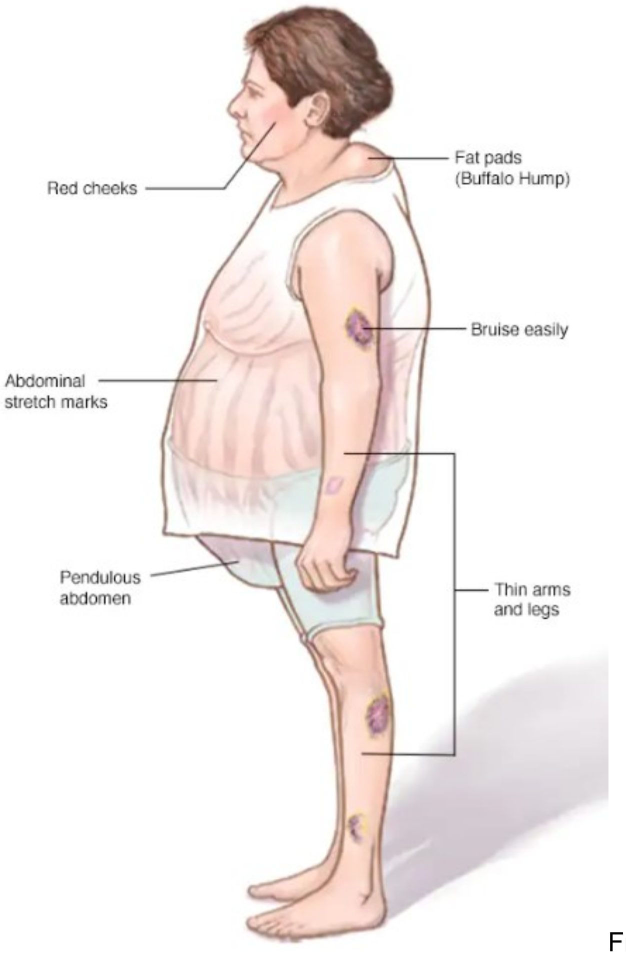


From *Cushing's syndrome* by Häggström, M., 2015.

(https://commons.wikimedia.org/wiki/File:Cushing%27s_syndrome.png)

The Cushingoid appearance is also quite distinctive due to physical symptoms: buffalo hump, red and round face (referred to as Moon face), thin arms and legs, dark red and purple stretch marks, central obesity (see Figure 4).

__Figure 4__ - Cushingoid appearance



From *Cushing's syndrome* by Mayo Clinic, 2023. (https://www.mayoclinic.org/diseases-conditions/cushing-syndrome/symptoms-causes/syc-20351310)

In addition to the physical symptoms caused by excess cortisol, around 50-85% of patients with CD experience cognitive impairments such as memory, attention and concentration difficulties, and changes in mood such as increased anxiety, irritability, depression, and panic attacks (Broersen, Andela, et al., 2019; Dorn et al., 1997). In rare cases, patients can experience psychosis, mania, and paranoia (S. T. Sharma et al., 2015). Tang and colleagues (2013) present two cases in which psychosis was the original presentation of CS, suggesting a high degree of awareness is required to ensure that a Cushing's diagnosis is not overlooked in psychiatric contexts. A. Sharma and colleagues (2018) found that in 35 CD patients with no previous history of psychiatric illness, 65% were reported to have psychopathology according to a Structured Clinical Interview for DSM-IV (SCID) including major depressive disorder, psychosis, and hypomania.

One of the biggest challenges of CD is that it can remain undiagnosed for several years as medical professionals tend to lack awareness of the disease, leading to delay and misdiagnosis in some cases (Brue & Castinetti, 2016). A meta-analysis of global data from 5367 patients including paediatric populations found mean time from first symptom to diagnosis for CD was 38 months (Rubinstein et al., 2020), however one of the included studies, a self-report study of 176 patients in Germany (Kreitschmann-Andermahr et al., 2015), found that the diagnostic process from symptom to diagnosis had a broad variation of 0 to 27 years. Valassi and colleagues (2022) also found that a small number of patients self-diagnose and must then convince healthcare professionals to order diagnostic tests.

The recommended first line of treatment for CD is pituitary surgery to remove the tumour. The surgery is especially risky as the tumour is usually very small, and the process of removing the tumour can lead to damage and/or impairment of the pituitary gland (The Pituitary Foundation, 2018). The pituitary gland is nicknamed the ‘master gland’ because it controls most of the major hormone functions. It does this by producing hormones that act on other hormone-producing glands responsible for essential human functions such as metabolism, sexual maturation, stress response and water balance, therefore impairment of the pituitary can have wide ranging effects (Society of Endocrinology, n.d.-c).

In his review of treatments for CD, Bertagna (2018) identifies the four-fold criteria for cure in CD: 1) Has cortisol excess been suppressed? 2) Is the pituitary-adrenal axis restored? 3) Have the symptoms of excess cortisol been reversed? and 4) Is the tumour gone? However, Bertagna also acknowledges that patients’ concerns lie with “the peripheral consequences of their disease” as opposed to biochemical markers (2018, p. 154). In fact, Carluccio and colleagues (2015) found that there was often discordance between patients’ self-assessed cure status versus their biochemical status and that around 22% of patients would report themselves as still suffering from the condition despite improved biochemical levels. This could in part be due to patients’ tendency to attribute enduring symptoms to CS and their perceived chronicity of it, which Tiemensma and colleagues (2011) link to negative illness perceptions (negative beliefs and understandings about the condition). However, clinical recovery after treatment is slower than biochemical remission and patients have reported being disappointed by how slowly functioning in daily life is recovered (Psaras et al., 2011). In addition, according to Pivonello and colleagues' (2020) review, 20% of patients do not achieve remission after pituitary surgery and 15% will experience recurrence after remission, sometimes many years later. At least one-third of CD patients require additional treatments and are not cured by pituitary surgery and reported recurrence rates have varied between 3-46% depending on the definition of criteria and duration of follow-up (Huguet et al., 2015; Pivonello et al., 2020). Literature has slowly been moving away from the term 'cure' towards the term 'remission', as long-term studies have reported recurrence in patients that had previously been declared cured (Hinojosa-Amaya & Cuevas-Ramos, 2021).

In cases of persistent or recurring symptoms, further surgeries are attempted which can lead to partial or complete removal of the pituitary gland. This is quite a drastic approach considering the importance of the gland and often leads to life-long medical dependency due to the loss of partial or complete hormone function. Wagenmakers and colleagues (2012) found that CD patients whose treatment resulted in hormone deficiencies reported significantly worse energy, motivation, and fatigue compared to CD patients left without hormone deficiencies. Alternatives to further pituitary surgery include medical treatments, surgical removal of the adrenal glands, and pituitary radiotherapy. In all cases, the goal of treatment continues to be to suppress the excess cortisol in hopes of reversing the course of the disease.

Unfortunately, even after successful treatment for CD, several symptoms persist, including physical, cognitive, and psychological impairments, which are believed to be due to structural changes in the central nervous system (Brue & Castinetti, 2016; Dorn et al., 1997; Huguet et al., 2015; Van Aken et al., 2005). In a global study of 320 CS patients, Valassi and colleague (2022) found that almost 90% of patients reported ongoing symptoms of fatigue, muscle weakness, and obesity/weight gain. Tiemensma and colleagues (2010) found that physical and psychiatric symptoms somewhat improved after successful treatment however patients reported feeling as though their functioning had not returned to pre-disease level, and an observational study by Acree and colleagues (2021) found over 30% of patients didn't feel prepared for the postsurgical experience.

Excess cortisol can lead to morphological changes in the brain such as atrophy and reduction of hippocampal volume and grey matter, which has been found to persist even after long-term remission and may account for the chronic cognitive impairments reported by patients (Wagenmakers et al., 2012). These include impairments in working memory, verbal fluency, spatial information, executive function, and mental fatigue (M. McBride et al., 2021; Newell-Price et al., 2006; Pivonello et al., 2017; Psaras et al., 2011). Psaras and colleagues (2011) found that younger patients reported higher levels of depression after treatment which they attributed to the loss of everyday functioning impacting their ability to engage in working life as they had before. Younger patients are more likely to have work demands placed on them and the frustration of being unable to fulfil these due to cognitive impairments is a possible precursor to depression. Indeed, The European Registry on Cushing's syndrome (ERCUSYN) project found that CS patients experienced significant job difficulties in terms of mental, physical, and flexibility demands, leading to a high percentage of health-related absenteeism (Valassi et al., 2011).

National Institute for Health and Care Excellence (NICE) guidelines on the management of brain and other CNS tumours, including pituitary tumours, suggest the psychological and social well-being of patients should be considered throughout and "Psychological assessment and support should be an integral part of the MDT management" (National Institute for Health and Care Excellence (NICE), 2006, p. 108). The guidelines also recommend the referral of patients to specialist psychology services and suggest ongoing training for all staff in providing support to both patients and relatives. Despite these clear recommendations and the well evidenced multidimensional impact of CD, Andela, Niemeijer, et al. (2015) found that certain areas of the condition were often overlooked by medical professionals, including the psychological and social aspects of the disease. This was put down to issues such as lack of time during consultation, patients being embarrassed about their thoughts and feelings, and not wanting to bother clinicians with what might be viewed as 'minor' problems (M. McBride et al., 2021). However, Gotch (1994) noted that although patients found it hard to volunteer information on their changing mental and emotional states, they were relieved to discuss these when asked. Valassi and colleagues (2022) found that the majority of patients did not receive multidisciplinary care from appropriate specialists, and Norman et al. (2022) report that

“Currently the most comprehensive package of psychosocial support available to UK pituitary patients seems to be limited to that offered by the Pituitary Foundation” (p.591), a charitable organisation providing information and support on managing pituitary conditions, medication, and dealing with psychosocial difficulties (pituitary.org.uk).

2.9.3. Secondary Adrenal insufficiency

After surgical intervention for CD, many patients develop secondary adrenal insufficiency (SAI), also known as Addison’s disease. SAI refers to when the pituitary no longer sends ACTH hormone signals to the adrenal glands, and these consequently stop producing cortisol (The Pituitary Foundation, n.d.). Although this may be a transient experience, around 42% of patients never recover adrenal function (Berr et al., 2015). SAI can be understood as the opposite of CD where symptoms are caused by low or complete lack of cortisol in the body. Symptoms of SAI include fatigue, headaches, low blood pressure, nausea, and feeling cold. As cortisol is essential for life, replacement in the form of hydrocortisone tablets is necessary, however it is difficult to mimic the body’s naturally fluctuating levels of cortisol. In their review, Gruber and Bancos (2022) found that patients often report symptoms of under or over cortisol replacement in SAI, and 45% of patients reported poor general health.

An important and life-threatening consequence of SAI is the risk of adrenal crisis, sometimes also referred to as an Addison’s or Addisonian crisis. Adrenal crisis refers to an acute manifestation of adrenal insufficiency whereby the level of cortisol in the body drops too low, which can lead to death. Adrenal crises are usually precipitated by stressful events such as illness or injury where the body would normally produce excess cortisol to manage, but due to SAI, cortisol levels do not meet the demands of the situation. Stressors or stressful events can range from major events such as undergoing surgery, experiencing severe shock from being involved in a road traffic accident, and battling an infection (e.g., flu, gastroenteritis), to less obvious stressors such as severe shock from bereavement, long haul flights, and diarrhoea (Gruber & Bancos, 2022; The Pituitary Foundation, n.d.). Adrenal crisis is the leading cause of death for patients with adrenal insufficiency despite cortisol replacement (Li, 2022) and patients with SAI are advised to wear medical alert jewellery and carry an NHS steroid emergency card. Broersen and colleagues (Broersen, van Haalen, et al., 2019) found that the incidence of adrenal crisis after CS treatment was substantial, and because of the range of symptoms already experienced by CS patients, recognising the signs of adrenal crisis can be challenging. Treatment for adrenal crisis involves taking extra hydrocortisone tablets or, if absorption is compromised or levels drop too low, administering an emergency injection of high dose steroid. The injection can be self-administered or administered by healthcare professionals, however Li (2022) found that patients with SAI reported higher levels of difficulty self-managing the condition and high likelihood of delays receiving treatment in emergency departments due to low awareness. As SAI/Addison's is also a rare condition, lack of knowledge and awareness for the condition can have dire consequences (P. McBride, 2013).

2.9.4. Health-related Quality of Life

Harvey Cushing, the neurosurgeon who first described Cushing's disease, identified psychological changes as a prominent feature of CD and valued the importance of attending to psychological wellbeing (Sulu et al., 2022). However, Sulu and colleagues (2022) highlight the tendency of endocrine research and practice to value hard data such as biochemical tests over so-called 'soft information' such as psychological wellbeing and quality of life. Nevertheless, researchers interested in the patient experience of CD have utilised measures such as Quality of Life (QoL) and Health-related Quality of Life (HRQoL) questionnaires (Nelson et al., 2013). QoL measures are said to evaluate physical and social functioning as well as other aspects such as life satisfaction and spirituality, whereas HRQoL measures focus on the impact of illness and treatment on QoL (Ho & Druce, 2018). Presented below are studies which have measured both QoL and HRQoL therefore I have used both QoL and HRQoL terms as authors have.

The areas of QoL and HRQoL research have received growing interest (Crespo et al., 2013; M. McBride et al., 2021) with Ho and Druce (2018) suggesting the high prevalence of QoL studies measuring changing QoL as the main objective signals the importance of improving QoL as a treatment goal. QoL tools are said to reflect "patient-related parameters" and are recommended in conjunction with biochemical and other "usual objective parameters" (Webb et al., 2017, p. 17). According to M. McBride and colleagues (2021), HRQoL measures can be useful in evaluating changes in the clinical course, particularly during follow-up. The information gathered through QoL measures intends to provide a more complete picture of the patients' condition by highlighting concerns that may not always be verbalised (Webb et al., 2017). HRQoL questionnaires enable clinicians to better understand the needs, fears, priorities, and expectations of patients and can therefore improve patient-clinician relationship and satisfaction of care (M. McBride et al., 2021). Generic QoL measures allow comparison across diseases or populations, whilst disease-specific questionnaires aim to highlight specific concerns for patients with a particular diagnosis (Ho & Druce, 2018).

Three disease-specific HRQoL measures have been developed which focus on the impact of CD and its treatment: CushingQoL (see Webb et al., 2008), Tuebingen CD-25 (see Milian et al., 2012a, 2012b), and QOL-CD (see Cusimano et al., 2020). CushingQoL was devised through interviews with patients and asks 12 questions which are answered on a five-point Likert scale, with the total score representing HRQoL (the higher the score, the better the measured quality of life). The Tuebingen CD-25 was generated through patient interviews, by reviewing the literature, and with ratings from medical professionals. The resulting 25 questions are also answered on a Likert scale, with the total score representing better or worse HRQoL (Badia et al., 2014). Finally, QOL-CD was developed through focus groups, literature searches, and validation of several versions of the questionnaire. The final questionnaire assesses 56 items on a three-point Likert-type scale in which 1 represents a good QOL and 3 indicates a poor QOL, on the six domains of general health, emotional health, physical health, mental status, social well-being, and medical treatment (Cusimano et al., 2020).

All three questionnaires are believed to assess aspects of HRQoL specific to CD such as physical appearance, mood, sexual activity, social concerns, pain, and health in the future. However, some studies continue to use validated generic QoL measures such as Health survey-short form (SF-36) particularly when drawing comparisons between different populations including healthy controls (Santos et al., 2019).

Studies that have looked at HRQoL in CD and CS patients during the course of the disease have found: lower overall HRQoL scores compared to healthy controls; issues in the physical dimension such as changes in appearance, pain, fatigue, sexual dysfunction and lower body image perception; depression and emotional instability; impaired performance at work and school; relationship problems including marital and friendship; and increased worry about health in the future (Andela, Scharloo, et al., 2015; Badia et al., 2014; Broersen, Andela, et al., 2019; Crespo et al., 2013; Huguet et al., 2015; Keskin et al., 2018; Knoble et al., 2018; Lobatto et al., 2018; Nelson et al., 2013; Webb et al., 2008).

In addition, HRQoL does improve after treatment/remission, however, remains worse than healthy controls. In a study looking at depression, quality of life, and body image in CD patients who had undergone treatment, Alcalar and colleagues (2013) found that CD patients reported worse QoL and body satisfaction, compared to healthy controls. Indeed, additional studies have found negative illness perceptions, enduring depression, anxiety and fatigue, and lower scores in general health following treatment and into long-term follow-up (Carluccio et al., 2015; Tiemensma et al., 2011; Van Der Klaauw et al., 2008). Van Der Klaauw and colleagues (2008) also found significantly impaired QoL for CD patients left with hormone deficiencies compared to those without hormone deficiencies and healthy controls.

In their review of QoL studies on CS, M. McBride and colleagues (2021) identified several determinants of QoL including delayed diagnosis, aetiology, hormone deficiencies and psychopathology. A survey by one of the study's co-authors undertaken as part of a doctoral thesis also identified unmet needs and areas for improvement relating to QoL, notably the lack of health professionals and public awareness of CS; and the need for more understanding of the psychological effects of the condition and subsequent psychological support needs (M. McBride, 2022). Another significant outcome of QoL studies is the importance of providing information to patients regarding treatment and outcomes to enable patients to manage expectations (Alcalar et al., 2013; Van Der Klaauw et al., 2008).

2.9.5. Issues with Quality of Life studies

The issue with using HRQoL questionnaires to capture the patient experience is that these measures focus on a functional definition of wellbeing, as well as an abstract concept called 'health-related quality of life' which lacks clear and consistent definition (Ogden, 2012). There is no single definition or conceptualisation of QoL (Ho & Druce, 2018), and the term is likely conceptualised differently by researchers, patients, and clinicians (Norman et al., 2021). The use of predefined scales and dimensions not only defines what outcome is for others, but it also pre-selects what is important whilst ignoring how the patients themselves construct their experience (Radley, 2000). Patients are expected to rate their feelings on a scale, having to distil their experience into something quantifiable. By focusing on scores rather than individuals, HRQoL measures bypass the patient's voice, which consequently bypasses their experience (Toombs, 1992b).

Knoble and colleagues (2018) point out that measures such as HRQoL are not suitable for rare disease patients as they measure HRQoL across two time points therefore only observing linear changes, whereas CS patients are likely to experience non-linear HRQoL changes, particularly during treatment. QoL measures also fail to reflect the dynamic nature of quality of life and often collapse all aspects of experience into one global score. As Tiemensma (2016) highlights, different domains may change over time, however global scores make it impractical to separate physical issues from psycho-social ones. Lastly, M. McBride and colleagues (2021) mention that QoL is a multifaceted concept that encompasses several domains including spirituality, however their review of HRQoL literature on CS does not include any data on spirituality. My literature search was also unable to identify any studies exploring the spiritual dimension of the CD experience.

Despite the growing body of literature on HRQoL measures, as a Cushing's patient I have never been asked to complete a QoL questionnaire, suggesting these measures are a far cry from being implemented in clinical practice, but rather remain tools of research. Ho et al. (2018) found that QoL measures are not routinely used with patients with adrenal insufficiency and suggest barriers to integration of QoL into clinical practice include affordability, disruption to clinical workflow, and uncertainties around whether QoL evaluations would add value to the clinical interaction. Norman and colleagues (2021) also suggest knowledge of QoL issues does not necessarily translate into meaningful support. Qualitative studies complement findings from QoL studies by adding subjective and contextual factors to gauge a more holistic view of the lived experience of CD.

2.9.6. Qualitative studies

Six qualitative studies including a doctoral thesis are presented below and highlight the paucity of qualitative research and first-person accounts in CD. I begin by presenting studies by Simpson, Heath, and Wall (2014), and Norman and colleagues (2022) that capture qualitative data on the experience of living with pituitary tumours, including CD, before presenting the only four qualitative studies identified focusing on the lived experience of Cushing’s.

The study by Simpson and colleagues (2014) involved synthesising the stories of eight participants living with a pituitary tumour, including one with Cushing’s disease, to identify structures and metaphors in their narrative. The methodological basis for the study was a narrative approach drawing on the belief that individuals attempt to gain an understanding of their experience through storytelling. Participants included were all diagnosed with a pituitary tumour and had stable hormone levels, with treatment undertaken more than 6 months before. Participants all shared holding expectations about a quick recovery process which was then negated by a slow recovery experience. The psychological impact of having a pituitary tumour was also unexpected by participants who described significant changes in their sense of self and relationships. Simpson and colleagues (2014) also highlight the lack of narrative structure around boundaries of time, where past and present challenges blur into one. They conclude by stating that the findings of the study highlight the therapeutic importance of giving participants an opportunity to share detailed accounts of their story.

Norman and colleagues (2022) undertook a survey with open-ended questions allowing content analysis of qualitative data. The analysis of 748 responses from participants, all members of The Pituitary Foundation with various pituitary conditions, revealed an overarching theme of ‘hidden disability’ further broken down into themes of physical and cognitive effects, emotional and behavioural issues, appearance distress, and social isolation.

Participants reported the lack of acknowledgement from medical professionals for their subjective experience, stating doctors tended to focus on ‘objective’ data arising from medical tests, largely ignoring any issues raised by patients if test results were within normal range. Fatigue was an often-cited example of a subjective state that cannot be measured through medical tests but has a big impact on participants’ day to day, forcing them to make choices on how to allocate available energy. Participants also reported a general feeling of being unwell, which is a vague and fluctuating experience and was often interpreted by medical professionals and others as somatising poor stress management rather than anything of concern.

Emotional and behavioural concerns flagged the need for counselling and psychoeducation support to improve levels of self-esteem, depression, anxiety, and mood swings. Appearance distress was identified in 510 surveys, and "respondents referred to some pituitary conditions as being 'hidden conditions' because the change in appearance that was significant to them as indicative of their illness was not interpreted as meaningful in the same way by others." (Norman et al., 2022, p. 593). Finally social isolation was experienced in both employment and relationships where participants reported lack of understanding due to the rarity of their condition and the fluctuating nature of symptoms. Participants also reported difficulty getting others to understand the severity of the condition. The condition and its impact on participants put a strain on relationships with family, friends, and partners.

Both studies on the experience of living with pituitary tumours highlight several important issues, namely unmet expectations of recovery, temporal disruption, the 'hidden' aspects of conditions which leads to misunderstandings and lack of support, and the importance of sharing the story and need for counselling. However, given pituitary tumours encompass a wide range of disorders with varying causes, symptoms, and treatment approaches, researching them together runs the risk of oversimplifying or generalising findings that may not apply uniformly to all conditions. The aim of this research is to elucidate the experience of living with and beyond CD, so it is perhaps more helpful to look at CD specific literature.

In the only journal published first-person account of CS, Armstrong (Armstrong & Fachnie, 1991) provides a phenomenological retelling of his experience with a rare form of Cushing's caused by a lung tumour. He speaks to its impact on all areas of his life and provides a personal (dare I say 'human') look at the illness. Fachnie, the doctor who encouraged Armstrong to share his experience, feels this account provides insight into the phenomenology of CS and allows other patients and physicians to "experience vicariously the tortures of the disease" (Armstrong & Fachnie, 1991, p. 9). However, no such account of the experience of CD has been published in scientific literature.

A study by Gotch (1994) utilised qualitative questionnaires to group and categorise recurring themes for 41 CS and CD patients. In the category of physical effects, fatigue/weakness was reported in 85% of questionnaires, and changes in physical appearance in 63%, with weight gain and moon face most mentioned. Loss of emotional stability (61%), impact on families and work/school performance, were also salient themes. Gotch (1994) identified that participants who viewed themselves as unrecovered were those still receiving steroid replacement or continuing to experience physical effects of CS, particularly fatigue and inability to lose weight. Participants in the study also suggested ways delivery of healthcare could improve, including being provided with more information on: the condition, treatment alternatives, dealing with steroid withdrawal, recovery, and illness management. On the social side: involvement of family, being linked to other CS patients and support groups were suggested. Participants also mentioned the need for more support, understanding, reassurance, empathy and listening from healthcare professionals. Patients want progress to be celebrated but for struggles to also be acknowledged and addressed, for example by referring to mental health service/professionals.

Although Gotch's (1994) study begins with first-person descriptive accounts of CS, participants were only asked to respond to questions falling within predetermined categories, with responses being analysed for categorisation and frequency to allow comparison with quantitative studies. Therefore, Gotch's (1994) study can be said to fall victim to the same criticism brought to QoL studies which fail to capture the richness of patient experience by focusing on scores/numbers rather than thick description.

With a clear focus on the richness of first-person accounts, the doctoral thesis by King (2003) employed a broad phenomenological approach to explore psychosocial factors involved in the patient experience and adjustment to CS. The aim of the research was to uncover significant aspects of people's experience of Cushing's syndrome. Drawing on theoretical models of *Common-sense model* and *Possible selves model* (as cited in King, 2003), the research questions ask: "How do patients with Cushing's syndrome understand their illness?" and "How does CS and patients' understanding of it - affect their identity, and how does identity influence representations*?*" (p.65-66). The researcher conducted unstructured interviews with 14 adults diagnosed with CD and one with CS who had undergone treatment in the past 3 years. Interestingly, the researcher found during the pilot phase of the project that asking specific questions during the interview 'stunted' participants' descriptions and that making space for spontaneous descriptions allowed for richer responses, leading to subsequent interviews being unstructured.

The findings were analysed using IPA which revealed two central themes: *Evolving understanding of illness* and *Transmutation of the self* (King, 2003, p. 91). Evolving understanding of illness encompasses changing perceptions due to the difficulty of participants to control and understand their illness, whilst Transmutation of the self highlights the impact of CS and the beliefs held by participants and their social context in “dissolving and eroding their identity” (p. 177). The study found expectations of recovery portrayed “a picture of restoration, undoing, and forgetting” whereby participants believed the removal of the tumour would “get the patient back to how s/he was before” (p.104) however the experience of CS leads to “*both* losing valuable past selves *and* looking forward to a new identity” (p.185). The study identified both internal and external changes to the body as contributing to the erosion of identity and highlights the importance of social information in framing patients’ understanding of their condition and its management, and in moderating identity challenges. The findings showcase experiences of being dismissed by medical professionals as well as participants experiencing personal criticism and blame from family and friends for CS and their slow recovery.

The possibility of recurrence and continuing effects of the condition and treatment lead participants to conceptualise CS as a complex and serious long-term condition. Given study participants shared finding the interview process healing and meaningful, one of the main clinical implications put forward by King (2003) is to support providing patients with an opportunity to reflect on the totality of their experience of CS which goes beyond physical and mental symptoms of disease. As this research was conducted 20 years ago, more recent accounts of the experience of living with CS might reveal whether individual and social contexts have changed.

A more recent study from Italy by Graffigna and colleagues (2020) was designed using Narrative inquiry. Twelve CD patients were recruited through specialist centres by endocrinologists and asked to keep a one-week diary on their experiences of living with the disease. The diaries, although intended to foster free expression, were semi-structured. These were aimed at eliciting narratives about the disease, how it progressed and how it was experienced. Emphasis was placed on the experiences pre- and post- treatment. Participants were also given the opportunity to include drawings and photos in the diaries, to allow for metaphorical and creative expression of feelings. They were then invited for face-to-face semi-structured interviews designed to explore insights emerging from diary entries. The data from diaries and interviews were analysed by extracting semantic and emotive units, and recurrent categories formed the seven main themes: 1) *The "Calvary":* the difficult path towards the diagnosis of Cushing; 2) *The "threatening shadow":* interviewees' representation of CD; 3) *"I'm unknown to myself":* their deteriorating self-image and consequent negative feelings; 4) *"I'm in a black-out":* the sense of lack of purpose in life and no sense of agency; 5) *"Please leave me alone":* the deterioration of social relationships; 6) *"The cost of my illness":* the perceived economic impact of the disease on interviewees' lives; 7) *"From frustration to rebirth":* the patients' therapeutic journey (Graffigna et al., 2020, p. 147).

The results speak to the trauma of being diagnosed with a "nasty, evil disease", the stigma and loss of self-esteem brought about by physical changes, and the profound sense of insecurity that ensues (Graffigna et al., 2020, p. 149). However, the study is not without its limitations. Firstly, participants were predominantly male (58%) which is not representative of the prevalence of women in Cushing's and may therefore present a slightly skewed perspective given the identified gender differences in CD (see 2.9.1.). One must also consider the potential for selection bias when participants have been recruited through their healthcare providers, as clinicians are likely to put forward patients with positive outcomes. Lastly, the interview questions were devised by the team rather than emerging from the data contained in the diaries, meaning the team defined what they considered important areas of research. Noticeably, the spiritual dimension of values, beliefs, and meaning is left largely unexplored.

Graffigna and colleagues (2020) point out that the scientific community has shown interest in patient engagement and has recently adopted new approaches to patient care. Studies so far on QoL in CD patients have used standardised measures aimed at assessing specific areas such as depression and anxiety and CD specific scales have provided better assessment of QoL but remain quantitative. Patient accounts of lived experience are key to providing insight into the expectations and needs of patients during treatment and the patient’s perspective is essential to developing sound clinical practice in healthcare.

2.9.7. Conclusion

Cushing’s disease is rare, difficult to diagnose, and difficult to treat. The symptoms of CD are multidimensional and impact several areas of life - physical, psychological, and social. Treatments for CD have varying degrees of success and rarely result in complete removal of symptoms. In most cases, patients are left with irreversible changes including having to learn to manage SAI. There is a plethora of evidence for long-term psychological and cognitive issues, and studies on quality of life consistently report poor long-term outcomes for CD patients compared to other pituitary conditions and healthy controls. Impaired QoL domains involve physical, mental, social, and functional wellbeing.

Although interest in the patient’s perspective is growing, research literature remains primarily quantitative with only four CS/CD specific qualitative studies identified (Armstrong & Fachnie, 1991; Gotch, 1994; Graffigna et al., 2020; King, 2003). Further qualitative studies on pituitary conditions have been discussed (Norman et al., 2022; Simpson et al., 2014), however an exploratory study on the experience of living with and beyond CD, such as the one outlined below, provides context and nuance to the idiosyncrasies of CD. The chosen methodology also ensures that the patient’s experience remains centrally focused as it does not predefine outcomes for its participants, but rather facilitates rich and detailed personal accounts. The use of the four dimensions as a heuristic tool also ensures a more holistic account that encompasses all dimensions of existence. The following sections outline methodology and the analytic process undertaken.

3. Methodology

"...human experience happens at the junction of subjective and objective experience." (Sultan, 2018, p. 76)

The research question asks: What is the experience of living with and beyond Cushing's disease? This chapter outlines how I undertook this project, the choice of methodology, and its philosophical basis. Alternative methods that were considered are presented to demonstrate the rationale for selecting Heuristic inquiry. This is followed by a description of the Heuristic method and how it informed the research design including the validity criterion and use of reflexivity. Details of the pilot study along with the participant recruitment and interview process are outlined. Finally, ethical considerations are presented, followed by a description of the transcription and analysis process.

3.1. Qualitative research

I opted to conduct qualitative research by reflecting on my research question and how best to answer it. Qualitative research is an inductive process that contrasts the deductive practice of quantitative approaches. Considering my interest in the lived experience, I knew that quantitative methods would never produce the rich, detailed accounts I needed to gain insight into the emotional, experiential world of my participants. Qualitative approaches are best suited to an exploratory study as they leave room for participants to challenge the researcher's assumptions by steering clear of predictive and reductionist tendencies (Willig, 2013). The qualitative researcher is encouraged to maintain an attitude of openness and curiosity, and there are no expectations or hypotheses guiding the qualitative process.

3.2. Heuristic inquiry

Given my own experience of CD, I sought an approach that would allow me to draw on this personal experience rather than try to exclude it. Heuristic inquiry (as developed by Moustakas, 1990) sees the researcher's personal and subjective experience of the phenomenon as an additional source of data. Heuristic research encourages passionate involvement in the topic to facilitate a deep and sustained exploration. The heuristic design encourages the researcher to discover new meanings and connections within herself, which enable different understandings of the phenomenon under research. She remains present throughout the process, engaging with the phenomenon in a creative and available way (Moustakas, 1994). For Hiles (2001), this use of self is likened to the practice of psychotherapy. Indeed, because of its congruence with counselling and psychotherapy, heuristic inquiry is well suited for research in the field of counselling psychology (West, 1998).

Rather than engaging solely with the participant's narrative descriptions, the heuristic researcher can also engage with personal documents, artwork, diaries, any other form of 'data' that depicts the phenomenon (Moustakas, 1990). The researcher becomes *bricoleur*, creatively using different methods or tools to create complex and meaningful understandings (West, 2007). She must be prepared to surrender to the process to allow her transformation to take place. The use of the researcher's autobiographical experience enables her to access the tacit dimension and share an understanding of the phenomenon on a level that cannot be verbalised (Moustakas, 1990). Participants are also named co-researchers to represent their involvement in the process and are portrayed as fully as possible to remain visible throughout the analysis. The terms *participant* and *co-researcher* are both used throughout the study.

The Heuristic approach is particularly suited to this research project in many ways. Portraying the co-researchers fully not only keeps them visible throughout the process but also gives them a voice (which individuals with rare diseases often lack in scientific and research fields) whilst respecting their need for confidentiality. My own experience of living with and beyond CD, and all the subjectivity and potential 'bias' this brings, is not ignored or hidden from the final project, it becomes the frame of reference that facilitates the co-creation of new understandings of the experience (Sultan, 2018). Although I acknowledge that the researcher position is an inherently powerful one, I truly feel that the heuristic attitude allows me to stand shoulder to shoulder with my co-researchers. The creativity and intuitiveness this approach encourages also fosters an embodied use of self, akin to therapeutic work. Just as the therapeutic process can change the therapist, so too can heuristic research change the researcher. Moreover, this transformation occurs on both research and personal level, which makes it particularly suited for doctoral research.

3.3. Philosophical basis of heuristic research

3.3.1. Ontological, Epistemological, and Axiological position

Ontology is concerned with the nature of reality, existence, and being. Research methodologies are anchored in ontological positions along a spectrum of realism and relativism. Realism posits there is a reality that exists independent of perception, whilst relativism acknowledges multiple constructed realities (Ponterotto, 2005). Identifying my ontological position was key to selecting how to undertake this project and my choice of methodology is underpinned by my beliefs that reality is relative, subjective, and influenced by context. Heuristic inquiry is an exploratory and relational process in which the relationship between researcher and co-researchers is essential to the co-creation of knowledge. My aim in using heuristic inquiry is therefore to facilitate the development of researcher and co-researchers' reality of living with and beyond CD, towards a synthesis of the essence of this lived experience. Each account highlights both individual and potentially universal facets of experience, whilst contributing to a co-created reality and meaning of the phenomena.

Epistemology deals with how we acquire or create knowledge, encompassing the relationship between researcher ('would-be knower') and research participants ('knower') (Ponterotto, 2005). The positivist and post-positivist paradigms employed in medical research, and most of the literature outlined in the previous chapter (see section 2.9.), encourage a dualist and objectivist epistemology whereby the researcher must remain independent of the 'knower' to capture unbiased data. In contrast to positivist approaches which emphasise objectivism and dualism, the heuristic researcher aims to foster dynamic and intersubjective relationships with study participants. A core element of heuristic research is the relationship between 'knower' and 'would-be knower' whereby the researcher and co-researchers hold both positions.

Finally, axiology is concerned with the values of the researcher and how these may influence the research process. Research into medical conditions rarely engage with the researcher's values as these are seen as impinging on the process. However, heuristic inquiry requires the researcher to be transparent and acknowledge her values and experience so as to bracket whilst recognising that values and biases can never be fully eliminated from the research process (Sultan, 2018).

3.3.2. Relationship to Phenomenology

Phenomenology is concerned with representing phenomena using rich and evocative narratives that capture their essential nature through intuitive and reflective embodied practice. Heuristic inquiry is a reflexive and relational approach to phenomenological research inspired by its concepts and drawing on the philosophies of Merleau-Ponty, Buber, and Gendlin (cited in Sultan, 2018). However, Douglass and Moustakas (1985) differentiate heuristic inquiry from phenomenology in several ways, asserting its unique and distinctive stance.

One of the key differences is the use of bracketing. Phenomenological research employs the methodological procedure of bracketing in an attempt to set the researcher’s values aside. Bracketing or epoché as outlined by Husserl (1913/1931) requires the phenomenological researcher to intentionally put aside personal beliefs, judgments, and theoretical frameworks to approach the phenomenon being investigated with an open and unbiased mindset. Conversely, in heuristic research bracketing is about identifying how the researcher’s values interact and contribute to the process. The focus of phenomenological research remains on structured experience as opposed to the personal meanings underscored by a heuristic attitude. This difference in focus leads to a distillation of co-researchers’ experience in phenomenological projects. Phenomenology is an embodied and reflective process and yet the body of the researcher is often missing in phenomenological research as the emphasis remains on co-researchers’ narrative accounts of experience. The heuristic researcher’s body, however, is seen and utilised as an epistemic tool, and both researcher and co-researchers remain visible throughout (Sultan, 2018).

The researcher’s insight and experiences are central to the research process though the most significant differentiating factor of heuristic research is that the researcher must have encountered the phenomena under research in a direct and personal way, which is not a prerequisite of phenomenological research.

3.3.3. Social constructivism and Interpretivism

Heuristic inquiry is a social constructivist approach at its core (Sultan, 2018). Social constructivism falls under the interpretivist umbrella which sits in counter-position to positivism’s paradigm of realism that asserts a singular, objective, and external reality. The interpretivist paradigm adopts a relativist position in which reality is subjective and constructed. My use of heuristic methodology reflects my belief that there is no single reality but multiple realities that are subjective and socially constructed. To derive essential meaning from lived experience, therefore, requires a thorough process of introspection stimulated by relational and dialogical interactions with co-researchers.

> Ultimately, heuristic inquiry allows us to transcend the specifics of personal experience and move toward the universally shared essential meanings of the topic of inquiry while maintaining the wholeness of what was shared within the research process, as well as the wholeness of those individuals who shared it. (Sultan, 2018, p. 28)

3.4. Alternative methods

3.4.1. Narrative analysis

I initially considered narrative analysis as a way to delve into the clinical narratives of CD patients. Clinical narratives present more than just descriptions of symptoms and physiological disturbances, but also include the patient's interpretations and understanding of their illness (Toombs, 1992b). Whilst current medical and research data present a biomedical view of CD, the patient's narrative presents the 'story' of the illness. Murray (2000) believes that narrative analysis is ideally suited to researching the impact of illness on people's lives as it assumes that individuals create stories to make sense of their experience and communicate it to others, therefore these can be considered primary sources of data. Narrative analysis places emphasis on the importance of language, talk, and the meaning-making capacities of people (for more on narrative analysis, see Riessman, 2008). Narrative-based medicine, which applies narrative concepts to medical practice, is also a growing field that not only suggests patient narratives are valuable sources of information, but that eliciting illness narratives is intrinsically therapeutic (Zaharias, 2018).

Whereas heuristic inquiry sees themes and concepts as co-created, the focus of narrative analysis is the individual story and interpretation by the researcher. Reflecting on the importance narrative analysis places on language, it did not seem an appropriate method for this research project. Narrative analysis' focus is on the construction of reality through stories and the reframing of existing narratives. In contrast, heuristic research utilises both verbal and non-verbal phenomena to create meaning of the experience itself through direct exploration and description. In heuristic research, the individual account is seen as just one example of the experience. Ultimately, I felt that narrative analysis lacked consideration for the embodied nature of experience whilst also placing the researcher in a passive position of 'listener'.

3.4.2. Interpretative Phenomenological Analysis

Interpretative phenomenological analysis (IPA) aims to explore the experience of participants with the assumption that their subjective account can provide insight into the thoughts, feelings, and beliefs they hold towards the phenomenon under investigation. IPA is an interpretative process influenced by hermeneutics, conducted through a series of steps and interpretive readings of data, during which the researcher identifies and formulates experiential statements into personal experiential themes and ultimately group experiential themes (for more on IPA, see Smith et al., 2022). The researcher is also encouraged to conceptualise the data in terms of psychological theory and constructs (McLeod, 2011). Contrary to narrative analysis, IPA views language as representational rather than constitutive. The researcher's own experiences and worldview are acknowledged as necessary prerequisites to understanding, suggesting IPA encompasses an element of reflexivity, however, the researcher's reflexivity is not theorised. IPA researchers are encouraged to engage in reflexivity throughout the process and to record thoughts, feelings, and reflections however this is done with the intent of bracketing out any potential bias. In heuristic inquiry, the researcher's personal experiences and self-reflection become part of the inquiry process. The researcher's insights and self-understanding are considered valuable data that contribute to the overall understanding of the phenomenon.

Although IPA was the first method that came to mind when I decided to explore the lived experience of CD, I came to realise this was out of familiarity with the process rather than as a result of epistemological reflexivity. IPA focuses on the psychological world of thoughts, meaning and processes, and therefore adopts a somewhat Cartesian mind-body duality, which does not fit with an embodied experience of illness. The lack of transparency regarding personal reflexivity is also problematic when working with a topic in which the researcher is so directly involved.

3.4.3. Heuristic self-search inquiry

Heuristic self-search inquiry (HSSI) was proposed by Sela-Smith (2002) in her critique of Moustakas' heuristic method which she labelled "a model of ambivalence" (p.53). For Sela-Smith (2002), a true heuristic inquiry does not require the inclusion of participants as this serves as a distraction from engaging in deep self-searching. She suggests it is the researcher's resistance to reconnecting with the *I-who-feels* which leads to a falling into the default position of researching others rather than oneself. Only by accepting to surrender to a deep self-search can the researcher experience transformation "that can impact the individual, society, and all of humankind." (Sela-Smith, 2002, p. 85).

The thought of undertaking this study using only my autobiographical data felt very anxiety provoking. I was plagued with worries about being judged for indulging in too much 'navel gazing' but also felt any publication of my thesis would be very exposing. Perhaps this was my resistance, because I did in fact find it challenging presenting my pilot study results (see section 3.7.). When contemplating whether to include participants, I also wondered if a study with only one participant, the researcher, would carry as much weight in a medical world that already favours large scale quantitative measures. Although my aim was an exploratory study, I must also acknowledge that I hoped the findings would support change and challenge the status quo in CD treatment. I was also holding in mind that patients with rare conditions often suffer from isolation, exacerbated by lack of awareness for the condition and lack of interaction with other patients. One of the things that brought me comfort early on in my CD journey was reading blogs of other CD patients. There was something validating about knowing I wasn't alone. By presenting only one voice, I might be reifying the notion that CD is an isolating experience of very few. By presenting multiple voices, I could show that rare does not mean alone, and would be giving representation to an otherwise underrepresented community.

Sela-Smith (2002) suggests using participants leads to no self-search or self-transformation however I argue that it is precisely the process of engaging with participant accounts that deepened my understanding of my experience and lead to transformation, although I did not know this would happen when I embarked on my journey and chose my methodology. However, Moustakas himself states that “Although in theory it is possible to conduct heuristic research with only one participant, a study will achieve richer, deeper, more profound, and more varied meanings, when it includes depictions of the experience of others” (Moustakas, 1990, p. 47).

3.5. Heuristic research method

3.5.1. Processes and Stages

The heuristic process is a demanding one that cannot be rushed and requires maturity, patience, and presence. The researcher must be willing to commit to a sustained and focused exploration whilst running the risk of opening old wounds in a quest for self-discovery and transformation (Moustakas, 1990).

Moustakas (1990) describes seven core processes necessary for heuristic research:

Identifying with the focus of inquiry – achieving an understanding of the question by getting inside it and becoming one with it.

Self-dialogue – engaging in a reflective process to gain a holistic understanding of one’s own experience of the phenomenon.

Tacit knowing – developing an implicit understanding of the topic through subconscious piecing together of individual parts.

Intuition – integrating tacit understandings with explicit knowledge.

Indwelling – returning to the phenomenon with unwavering attention to seek a deeper understanding of its meaning.

Focusing – staying with the researcher’s experience of the phenomenon to bring new knowledge into awareness.

The internal frame of reference – contextualising all knowledge against the backdrop of the researcher’s internal frame of reference.

These processes allow the researcher to enter the six stages of heuristic research: **Initial engagement**, which involves defining the area of research; **Immersion**, during which the researcher immerses herself in the topic, noticing the phenomenon in everyday life; **Incubation**, moving back from the data to enable tacit and implicit understandings to surface; **Illumination**, the process of reaching a new level of understanding through openness and intuition; **Explication**, the critical analysis of this new understanding which leads to a depiction of the essence of the phenomenon; and **Creative synthesis**, the creative depiction of the core themes and components of the phenomenon. The depictions and creative synthesis are checked and rechecked against the data as well as with co-researchers, to ensure they reflect the essences and meanings of the phenomenon as described (Moustakas, 1990). The six stages of research should not be considered linear as the core processes of heuristic inquiry may compel the researcher to move back and forth in search of deeper understanding.

The data is gathered through dialogues with the self and with co-researchers. These are conversational interviews in which no structure or pre-set questions are defined, however, an outline is set to provide topics and issues that can be explored with all co-researchers. I chose to employ van Deurzen's (2015b) four worlds' model as heuristic device. Unlike other interview formats, the heuristic interview does not impose a limit nor restrict the duration of the conversation, rather it encourages the dialogue to reach a point of natural ending. The lack of formal structure in this interviewing format is to encourage the expression of ideas, images, thoughts, and feelings (Moustakas, 1990). Moustakas (1990) also suggests the use of self-disclosure by the researcher as this helps build trust and can facilitate richer depictions and a deeper engagement within an I-Thou framework (Buber, 1970). Interviews are recorded, and notes taken immediately after to capture initial reactions. Co-researchers are also asked to share personal documents that capture their experience.

3.5.2. Validation in heuristic research

Heuristic inquiry is concerned with the subjective nature of human experiences and aims to provide a deep understanding of those experiences rather than generalisable conclusions. Consequently, validation in heuristic research is primarily concerned with rigor, trustworthiness, and the meaningfulness of findings within the context of participants' lived experience. Moustakas, drawing on Polanyi (cited in Moustakas, 1990) suggests a process of verification which sees the researcher returning again and again to the data in a rigorous and disciplined way, in which only she can “make the ultimate judgement” (p.33). This verification is further enhanced by asking co-researchers to comment on the comprehensiveness and accuracy of creative depictions.

Methodological rigor is validated through consultation with peers familiar with heuristic inquiry to verify the process and findings. In the context of a doctoral thesis, the thick description of the process and findings allows critical evaluation throughout the project by supervisors, but also through the final viva in which the researcher must defend her work. Moustakas (1990) also points to dissemination and publication as “a way of taking responsibility for the depictions” (p.34).

3.5.3. Limitations of heuristic research

Specific limitations identified within this study are explored in further detail in the discussion chapter (see section 5.2.) however it is helpful to consider limitations inherent to the heuristic research method. Heuristic inquiry does not have clear or strict procedural steps for which Frick (1990) identified that the creative freedom this affords could potentially lead to undeveloped research and irresponsibility on the part of the researcher. Indeed, although Moustakas outlines processes and steps for inquiry, these are subject to under- (or indeed over-) engagement by the researcher whose relationship to the phenomena under research may fluctuate throughout the project and may therefore lead to resistance as suggested by Sela-Smith (2002). Logistical constraints of time and money may also rush the research endeavour which has been described as one requiring patience and presence.

Given the researcher’s own experience and interest in the phenomena under exploration, confirmation bias is a possibility which might lead to focusing or highlighting themes that confirm rather than challenge her own experience, and potentially overlooking essential aspects of phenomenon that don’t fit in her internal frame of reference. However, researcher and confirmation bias are a possibility in all research, and it is the transparency and reflexivity of the heuristic process which serves to counter this.

3.6. Reflexivity

As outlined above (see section 3.3.2.) *bracketing* is the process of identifying the researcher's assumptions and biases and setting these aside to approach the topic of inquiry with an attitude of 'not knowing'. As heuristic inquiry uses the researcher's own experience, bracketing is no longer about separating these attitudes from the process but rather critically evaluating them regarding the topic of inquiry and locating the researcher within the study. Etherington defines researcher reflexivity as the capacity to be aware of "how our own thoughts, feelings, culture, environment and social and personal history inform us as we dialogue with participants, transcribe their conversations with us and write our representations of the work" (2004, p. 32). To ensure transparency, I have shared my personal experience of CD and how I came to undertake this research project in the Introduction (see section 1.2.). A creative depiction of my experience along with excerpts from my own interviews are included in the Findings section (see section 4.) demonstrating how my experience fits within the study, and the following section outlining the pilot phase also elucidates my decision to use myself and to be interviewed by my therapist. I have also reflected on the process of undertaking a heuristic study into my own condition in the discussion chapter (see section 5.3.) and have tried to weave elements of reflexivity throughout this thesis.

Reflexivity enables the researcher to place her values, beliefs, and biases into perspective and research journaling is often suggested as a way to reflect throughout the process (Sultan, 2018). My method of journaling throughout has been to write free-flowing thoughts and what I call 'musings'.

> *Perhaps my greatest challenge has been starting the process and keeping momentum. I have remained in the initial engagement and immersion stages of my research for far too long, paralyzed by my fear of not doing this topic justice.*
>
> *I often have this sense of overwhelm, as though my experience of Cushing's is so immense yet also fragile, that trying to tackle this research feels like attempting to pin down a hot air balloon whilst being inside it!*
>
> *Extract from research journal, 6th March 2021*

Further excerpts from my research journal are included in following sections to ensure transparency throughout.

Etherington (2004) suggests researchers may shy away from including reflexivity in their writing for many reasons including fear of judgement and shame, as well as perhaps lacking the level of self-awareness required to recognise associated thoughts and feelings. Although I do not feel lack of self-awareness is an issue for me, I can certainly relate to fear of judgement and shame. This fear has been present throughout the many years it has taken me to complete this project. Even acknowledging how long this thesis has been in the making leads to self-judgement stemming from beliefs around productivity and shame around being ill. Over the years journaling has been a valuable resource however I have also found it helpful to use supervision, and at times personal therapy, to reflect on things that have come up through the research process. The supervisory relationship is an important vehicle that allows the researcher to process what has been experienced and learned (Etherington, 2004). I can certainly recall many conversations with my supervisor during which I would begin in a chaotic and anxious state, feeling overwhelmed by whichever task I was trying to tackle that day. Her calm and assertive voice would imbue me with confidence and help me step back and out to ‘see the wood for the trees’. The heuristic process can be challenging and interspersed with moments of uncertainty and loss of clarity. In these moments, Sultan suggests the researcher allow herself to “dwell with the uncertainty” as a means of maintaining a heuristic attitude (Sultan, 2018, p. 102).

Etherington (2004) suggests it may be beneficial to engage in therapy during research to ensure researchers do not suffer and I certainly found being in personal therapy throughout provided me with a safe space to explore the many thoughts and feelings that came up. This was particularly needed when I experienced moments of deep existential dread often triggered by engaging with CD and SAI literature highlighting my increased mortality risk. I also experienced periods of despair when I could not imagine finishing this project due to repeated bouts of illness, and sadness due to losses in my personal life. However, I have also been able to reflect on and acknowledge my personal growth through this process and this is expanded on in the discussion chapter (see section 5.3.).

As I'm reading literature on chronic illness and the effort it involves I'm realising that a lot of my challenges have been coming to terms that I am left with a chronic illness that may never improve. I had the impression that I had an acute condition - CD; and that once it was treated I would be fine/back to normal.

But it is only really just dawning on me that this isn't the case and that now I have to learn to adapt to my new way of being-in-the-world. For example, it is only recently that I realised I have a disability and that I am entitled to ask for help at work. For a long time I did not dare/felt embarrassed. Now I realise it's my right and I'm kind of pissed off that I never got the support I needed.

Extract from research journal, 25th March 2021

3.7. Pilot

As heuristic research begins with the researcher's autobiographical experience, I chose to be the pilot participant and opted to be interviewed by my therapist. Capturing my own experience through an interview process not only allowed me to establish my frame of reference which Moustakas (1990) states is essential to accessing the tacit dimension, but also allowed me to experience the process as my co-researchers would.

The interviews took place face-to-face, several months before the start of the COVID-19 pandemic. In keeping with the conversational approach as suggested by Moustakas (1990), I did not provide the interviewer with a schedule however gave her some direction regarding areas of exploration: a) **Physical**: attitudes towards health and illness; physical changes and limitations; body image; b) **Social**: interaction between culture and understanding/experience of illness; engaging with the social world; c) **Psychological**: sense of self and identity; relationships with intimate others (e.g. parents, partners); d) **Spiritual**: beliefs and values; attitude towards life; sense of meaning and purpose. As an existential therapist, she was familiar with the four worlds model (outlined in section 2.4.).

We set aside two hours for the interview and debrief. The interview lasted one hour and 39 minutes, which I found very tiring, and did not come to a natural close but rather was closed down as I began experiencing a headache. We agreed it would be best to schedule a second interview as I still felt there was more that I wanted to explore. The second interview took place three weeks later and lasted 62 minutes. I found it helpful to have some time between interviews as it allowed me to process what had been brought up.

As a participant with knowledge of the research aims, I felt that I somewhat held the four dimensions in mind, however the interviewer was also very good at orienting me and it felt very engaging to be asked questions directly stemming from the interview rather than pre-determined questions. Experiencing what it was like being interviewed gave me insight into what my participants might encounter. The first thing I noticed was that this felt like the first time speaking about and reflecting on my CD experience as a whole. Although I had been immersed in it through lived experience and through engaging in the research, having to piece it all together was very emotional, therapeutic, but also exhausting.

The process also made me cognisant of the impact of dual relationships, e.g., therapist/interviewer. I became aware when transcribing the interviews that the interviewer asked some leading questions, likely because of her knowledge of my experience with CD due to our therapeutic relationship. I became mindful of ensuring my questions and prompts remained open and curious throughout the interview to limit being too leading, however I did also want to ensure I explored or at least enquired about each dimension of experience.

3.7.1. Pilot transcription and analysis

I have plotted the transcription and analysis of the pilot along the six stages of the heuristic process:

1. **Initial engagement**/identifying focus had been an ongoing process for several years and began before data collection.
2. **Immersion**: I listened to the interview recordings several times to immerse myself in the data and began transcription using the Trint automated transcription service. I then went through the recordings again to check for transcription errors. This stage involved a lot of *self-dialogue* whereby I engaged in the emotional and sensory experience.

   Once both interviews were transcribed and checked for errors, I proceeded to read through each transcript several times. During this process, I tapped into *tacit knowledge* to select powerful quotes and assign preliminary codes/themes – this led to a total of 36 themes. At this stage, I opted to use NVivo for ease of coding.

3. **Incubation**: After the initial coding process, I took several months away from the research as I was dealing with personal issues. When I felt ready to engage with the process again, I found it very difficult to gain momentum. At this point, I engaged in a lot of personal therapy and research supervision to explore my feelings of stuckness. Eventually, I was able to return to the transcripts, reading back and forth between quotes and themes, opting to remove themes that no longer stood out and also combining themes that intuitively fit together. This process also led to a splitting of themes and the creation of seven additional themes, making a total of 43.
   I exported the themes and quotes to Word to create a table and write thoughts/notes about each quote (Appendix A). This stage was characterised by intense periods of reflexivity and *indwelling*.

4. **Illumination**: To make sense of the phenomenon in its entirety, I printed out all 43 theme names and cut these out into cards. I then placed the cards on a table and proceeded to group them intuitively. Thinking about the four dimensions of existence, I located the themes and groups under each dimension. It is at this stage that I identified the additional Temporal dimension. To visualise the relationship between the dimensions and this additional Temporal world, I created a representation (see Figure 5).

5. **Explication**: I engaged in *focusing* by continuously verifying the combinations and themes using quotes and the context of the transcript. Using *intuition*, I was able to differentiate between themes and sub-themes, reducing to 16 main themes located under the five dimensions of Physical, Social, Psychological, Spiritual, and Temporal.

6. **Creative synthesis**: As part of my doctoral studies, I had to submit a write up of my pilot study and present the findings. When it came to writing up my findings, I struggled to find a researcher voice that was distinct from my autobiographical voice. This highlighted the challenge of co-creating knowledge with self as ‘knower’ and ‘would-be knower’. To

address this issue, I consulted with my research supervisor to identify the mental barriers I needed to overcome and chose to present the pilot findings by using the pseudonym Kayla as a way to differentiate between the researcher and autobiographical voices. I also created a poem using extracts of the verbatim transcript to convey the results of the pilot study and this felt so meaningful. Although reading it aloud during the presentation was very vulnerable, I also felt this was a powerful way to convey my experience.

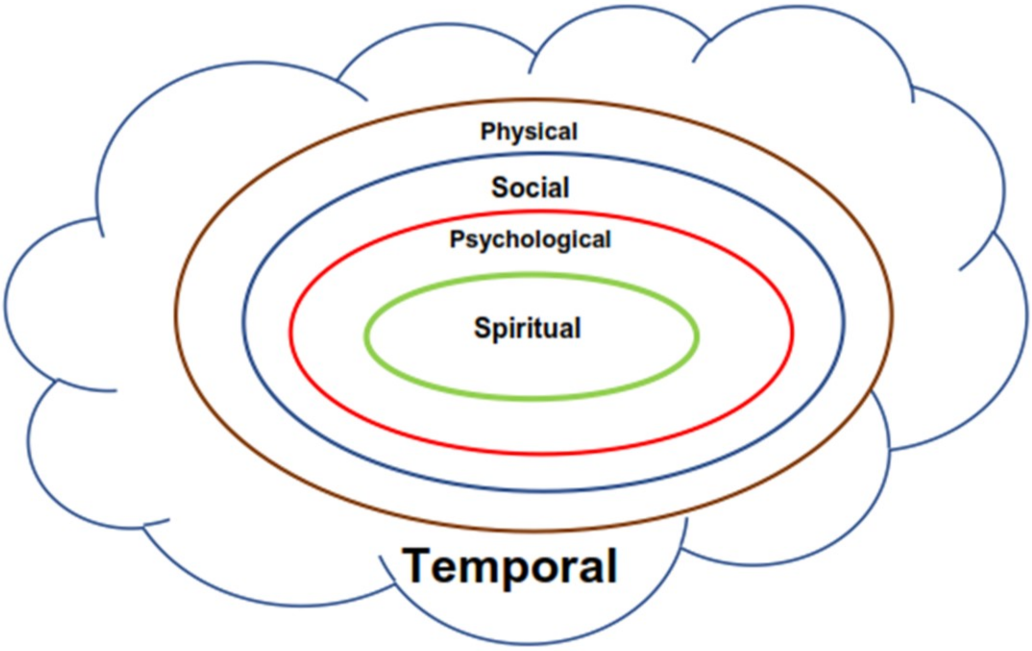
As I'm writing up my findings, I am finding it very bizarre talking about myself as a third person. This process of having to try and detach myself from the data to ensure I stay with it is such a contrast to the immersion that I have been engaging in for so long.

Extract from research journal, 12th February 2021

3.7.2. Preliminary findings

Analysing the pilot interviews revealed the addition of the Temporal world as a separate yet interrelated dimension of existence. Van Deurzen suggests that time is “another dimension that needs to be plotted and explored in any research” (2015b, p. 79) and presents Heidegger’s Ecstasies of time as a timeline tool, however she does not incorporate a temporal world in her framework as she differentiates between space and time. I created my representation based on findings (see Figure 5) and chose to represent the Temporal world as an overarching concept that is ethereal and ubiquitous, hence the choice of a cloud image. The relationship between illness and time has been explored in the literature review (see section 2.6.) and I was keen to see how participants experienced and discussed time.

Figure 5 *- Spatiotemporal dimensions of existence*



Thinking about my dimension of time, and reading van Deurzen's article about SEA and the dictionary of existential psychology and counselling. I'm wondering if there is more to time that I need to explore. How does illness fit within time? Time according to van Deurzen is something that we are in. Time is definitely subjective but is also objectively measured through calendars and clocks. And time is marked by events like birthdays and new year. How does illness fit in this?

What about the social aspect of time? Or the social and cultural meaning of time? Each culture has rituals linked to age e.g. quinceañera, and there are societal norms around time and age e.g. when one should be married, have children, when one is considered an adult.

And there is an expectation around when in time one should become seriously ill, i.e. that is the domain of the 'old'. You always hear things like: "oh they are so young to have cancer." - but since when does illness discriminate by age?

Then I am also thinking about the paradoxes and issues in the dimension of time - what might these be?

I think I want to spend some time reading more about time and how philosophers have written about time. I also want to look at van Deurzen's four worlds and the paradoxes to think about how the time element might work in a similar structure, or not.

Perhaps the dimension actually shouldn't be called time, but Temporal - see Heidegger 'Zeitlichkeit'.

Is there in fact such a thing as Zeitlichwelt?

Extract from research journal, 8th March 2021

The preliminary findings also suggested an abundance of concerns in the social dimension. This speaks to the socially constructed and relational aspects of illness whilst also perhaps highlighting some of the unique challenges of having a rare condition. Lack of knowledge, understanding, and awareness for rare conditions have been briefly addressed in the literature review (see sections 2.8. and 2.9.6.) and the pilot findings reflected similar issues. However, the addition of co-researcher accounts illuminated the experience of CD further.

3.8. Recruitment

I set out to recruit five participants as I hoped to capture rich detailed data and with the addition of my own interviews that would make six accounts.

3.8.1. Recruitment criteria

The inclusion criteria for participation were:

- **Aged 18 and over** – to provide informed consent.
- **Diagnosed with Cushing's disease 2+ years ago** – Webb et al. (2008) found that Cushing's symptoms and impairments were worse within 2 years of diagnosis which is why I chose to exclude those diagnosed in the last two years to ensure ethical treatment and reduce possibility of unnecessary harm, even though this may have resulted in excluding part of the experience.
- **Cured, in remission, or still experiencing symptoms -** Despite being in remission by medical terms, I am still suffering with remnants of CD therefore I felt that the lived

experience of illness was not limited to the symptomatic stage and could be explored in all stages.

- **Living in the UK** – my original intent was to conduct all interviews face to face with participants living in the UK. Unfortunately, due to COVID-19 interviews had to be done online however I decided to still limit to participants living in the UK to be able to situate their experience within my own frame of reference. I am aware from interactions with CD patients in other countries such as the USA that different issues arise due to differences in health service delivery and cultural context.

The exclusion criteria were:

- **Under 18 years of age** – vulnerable group requiring additional consent.
- **Diagnosed in the last 2 years** – see above.
- **Experiencing acute mental health issues** – it can be difficult, even distressing, to talk about experiences of illness and suffering, therefore I chose to exclude those currently in acute mental distress to ensure they are protected from further harm. I had taken into consideration my ability to contain and support my participants beyond the interview encounter and on that basis, decided not to include vulnerable adults due to the limitations of my reach. Each potential participant was triaged at first contact with a view to exclude those in acute mental distress for safeguarding purposes.

All participants were asked to confirm they had been diagnosed with Cushing's disease due to a pituitary tumour. This was made clear on the recruitment advert and in the initial triage call (see section 3.8.3.).

3.8.2. Advertising

An A4 recruitment advert was created which outlined the title of the study, the eligibility criteria, what the study would involve, and my contact details for further information. The ad also specified this research was being conducted as part of a doctoral thesis project (Appendix B).

Participants were recruited with the help of The Pituitary Foundation, a UK charity supporting those in the pituitary community (pituitary.org.uk). The recruitment advert was forwarded by the charity's

Head of Patient and Family services to the Admin of the ‘Cushing’s UK’ Facebook group. Although this group is managed by volunteers from The Pituitary Foundation, group members do not need to be members of the charity.

The admin posted the recruitment ad the same afternoon she received it and by the end of the day I had been approached by ten potential participants. Given the enthusiastic response received, I opted not to pursue any further recruitment avenues until I had confirmed how many participants were eligible. After initial contact and triage, I had five eligible participants who agreed to take part, so I did not need to recruit any further. The speed and ease of recruitment is discussed in the discussion chapter (see section 5.3.1.).

3.8.3. Initial contact and triage

Ten participants contacted me by email within a few hours of the ad being posted to the Facebook group. Three participants stated in their initial email they did not fully meet the inclusion criteria. I replied by thanking them for their interest and stating unfortunately they would not be able to participate but that I appreciated this could be disappointing therefore offered to organise a call to discuss this further. All three participants replied saying they understood and did not need to discuss but wished me luck on the project. One participant did express disappointment and shared finding it hard getting support for CD, so I provided them with the resources section of the debrief form which signposts to support organisations.

An email reply was sent to the other seven potential participants thanking them for their interest and asking to organise a quick telephone conversation to outline the research and confirm eligibility (Appendix C). At this stage one participant withdrew due to family circumstances, so telephone calls were organised with six participants however one participant did not respond to the invitation to initial call/triage. In total, five calls were completed with all five participants eligible and interested in taking part. The calls served to triage potential participants, ensuring they met the eligibility criteria and that it would be safe for them to participate (see section 3.10. for ethical considerations taken). To ensure I covered everything needed I created a crib sheet to use for all interviews and made note of the information provided by potential participants (Appendix D).

3.8.4. Demographics

All participants triaged went on to take part in interviews and identified as female. Four described their ethnicity as white British, and one stated she was mixed British. Ages ranged from 38 to 69. Three were in employment or self-employed, and two stated they were unable to work due to disability. Time since diagnosis ranged from three to nine years, with time since treatment ranging from three to seven years. A table detailing demographics is presented in the Findings section (see section 4. Part 1).

Although I suspected my experience of being a woman with CD contributed to shaping my experience, I did not set out to recruit an all-female cohort of participants. In fact, I wasn't sure how challenging recruitment would be, so intentionally kept my inclusion criteria broad. Demographics are explored further in the discussion chapter (see section 5.3.).

3.9. The research interview

In keeping with Moustakas' method I opted to conduct unstructured interviews. Nevertheless I started each interview with a broad open question to facilitate exploration: "Could you please tell me about your experience with Cushing's disease?". As outlined above (see section 3.5.), in order to collect rich and descriptive data from each participant, I employed the four worlds model (van Deurzen, 2015b) as a heuristic device, meaning that although the interviews were conversational, I held areas of interest in mind. These were: a) **Physical**: attitudes towards health and illness; physical changes and limitations; body image; b) **Social**: interaction between culture and understanding/experience of illness; engaging with the social world; c) **Psychological**: sense of self and identity; relationships with intimate others (e.g. parents, partners); d) **Spiritual**: beliefs and values; attitude towards life; sense of meaning and purpose; with the added **Temporal** dimension: Relationship with time; Past and future; Present; Timeline.

I kept a sheet in front of me during the interviews with each dimension set out so I could make notes and track areas of exploration (Appendix E). Each participant touched on all topics organically except the spiritual dimension which required some prompting. One participant spoke about her faith and religion without any prompting, but others were asked whether they had thought about the meaning of their condition or held any beliefs, which every participant responded in detail to, suggesting it is an area that is of interest. The study by Gotch (1994) found that there are areas patients may not bring up themselves but are happy to speak about if asked.

Every participant asked at some point during the interview where my interest in CD stemmed from and I disclosed that I had my own lived experience of CD. Moustakas (1990) suggests self-disclosure can help build rapport and every participant expressed some surprise but then communicated gratitude or encouragement for me undertaking this research. In his doctoral research, King (2003) found that he needed to clarify to participants that he was not part of the medical team as interviews tended to focus on symptoms rather than lived experience. It is possible that since my co-researchers saw me as 'one of them' they felt more comfortable speaking openly about their lived experience rather than feel the need to speak in a medicalised way. One drawback however was that participants also tended to make assumptions about my understanding of their experience by making statements such as "as you know". In order not to take anything for granted and ensure I remained open and curious I would always explore these points and seek clarification. This is addressed in the Discussion chapter (see section 5.3.4.).

3.9.1. Interview format

Due to the COVID-19 pandemic, all interviews were conducted over Zoom - a GDPR compliant platform that ensures end-to-end encryption. New Zoom meeting invites were sent for each interview with guidance on how to use Zoom.

Risk assessments were not needed as interviews were conducted online however at the start of each interview participants were asked if they felt in a comfortable location able to speak freely. I advised them the interview was set up to last 90 minutes, but that we didn't have to go for that long, the interview could be stopped at any point, and we could schedule a second interview if wanted. The Participant Information Sheet (Appendix G) also mentioned the potential for a second interview. During the pilot stage, I chose to conduct my interview over two meetings as when the first interview ended I felt I had more to share, consequently I wanted to provide each participant the same choice of more time. I also encouraged them to let me know if they needed to take a break at any point. Finally, I outlined the process of follow up if we had technical issues such as connectivity problems.

The shortest interview lasted 80 minutes with most participants choosing to utilise the full 90 minutes. Only one participant opted for a second interview which occurred two weeks later and lasted 60 minutes.

3.9.2. Consent and Participant information

As all interviews took place online, a copy of the consent form (Appendix F) and participant information sheet (Appendix G) were sent beforehand to allow time for consultation. This was done using Eversign (now called Xodo sign) which allows secure delivery and electronic signing of documents which can be downloaded by both parties. At the start of each interview, I confirmed that the participant was still happy to proceed and was aware of their right to withdraw. Consent was confirmed each time. Verbal consent was also given to record the interview, which was done using Zoom's built in recording facility allowing video and audio recording, and a small digital recorder as back up.

3.9.3. Debriefing

Around the 75-minute mark and during a natural pause in the conversation, I checked in with each participant signalling that we were approaching the allocated interview time. I offered a space to bring any final thoughts or reflections participants might have on the process, along with the opportunity to organise a second interview. I also explored whether they were left with anything or had any questions. Participants were invited to share any additional materials such as artwork, poems, journals, etc, as outlined in the participant information sheet. Once all final thoughts and questions were addressed, participants were advised I would email a debrief form and remained available to answer any questions. I also reminded each participant of their right to withdraw.

The debrief form thanked them for their participation and included contact details and resources for further support (Appendix H).

3.10. Ethical considerations

As a graduate member of the British Psychological Society (BPS) I consulted the "Code of human research ethics" (British Psychological Society, 2014) for guidance along with Middlesex University and New School of Psychotherapist and Counselling (NSPC) guidelines. The research project received full ethical approval from the NSPC research ethics sub-committee (Appendix I). To ensure confidentiality and ethical treatment of co-researchers, information was provided at initial point of contact detailing the nature and purpose of the project, and every potential participant was triaged by telephone. The potential risks of the research were discussed, and each prospective participant was asked whether they were currently accessing mental health services and/or experiencing any mental health issues (e.g., schizophrenia, bipolar, depression, anxiety, suicidal thoughts/ideation). A couple of participants shared experiencing some anxiety and depression with one stating she was taking anti-depressants. I explored the situation further with them to understand what symptoms they were experiencing to assess if these were significant, enduring and/or distressing, whether they were receiving any treatment, and what support they had in place. This part of the triage call involved risk assessment and use of clinical judgement to ensure participation was safe. Both participants reported mild and well managed symptoms along with good support in place which felt safe for them to proceed with participation.

All participants were sent a clear participant information sheet and consent form outlining the voluntary nature of their participation and their right to withdraw at any point without consequence, how to submit feedback, how the material they provide would be used, and how their confidentiality would be respected. During the transcription process participants were assigned a pseudonym and referred to only by this pseudonym in all documents. To ensure confidentiality, all specific identifiable details in verbatims were changed. Only one electronic file containing all participant details such as real name, pseudonym attributed, contact details, and demographics was created and was password protected and encrypted. All electronic data such as notes, transcripts, interview recordings and personal documents was password protected and encrypted in a cloud storage system and on an external password-protected hard drive. Physical data such as interview tapes and personal documents were kept in a locked safe box. After each interview, participants were provided a debrief form containing information on services that provide support to ensure their psychological welfare was maintained. Co-researchers were also given the opportunity to review their transcript, poem, and pseudonym.

Talking about illness and experiences of suffering can be distressing. Researchers are responsible for ensuring the safety of all participants and themselves. A fundamental element of ethical research is engaging reflexively and remaining attentive to how you respond and process interactions with co-researchers according to your internal frame of reference (Sultan, 2018). Strategies for minimising risk in the heuristic research process include making use of research supervision and consultation and allowing space between interviews for reflection (Sultan, 2018). Details of how I maintained my wellbeing as researcher are outlined above (see section 3.6.).

3.11. Transcription

I initially planned to transcribe each interview within 24 hours and before undertaking a new interview, however because of the quick responses received to the advert I did not want to lose momentum. I was also working part-time in the NHS, seeing an influx in demand for our services due to COVID-19, and was therefore limited in time. I made the decision after consulting with my supervisor that I would schedule interviews in when possible and undertake transcribing afterwards. In the end this worked out well as having all the interviews within a period of a few weeks created a real sense of *immersion*. I then spent several weeks engaging with the data by first listening to all the recordings.

All interviews were video, and audio recorded, and these were downloaded from the Zoom server. I started transcribing verbatim using Word but struggled with concentration and ache in my hands. Difficulty concentrating was not a reflection of my engagement with the data but rather the state of my health at the time likely exacerbated by the stresses I was experiencing at work. At this point I decided to use an AI transcription service as I had done for my pilot interviews and chose to use Otter (otter.ai). Otter uses AI software to transcribe audio files however it is prone to errors. Although using Otter saved me quite a bit of time, I still went through a very systematic review of each recording and transcript for accuracy. I chose not to alter any of the verbatims including leaving repeated and filler words. My decision to keep these was linked to my audiovisual memory which found it helpful to read repetitions or filler words as I could then recollect audio or visual memory of the participants' expression which added a dimension to the data. All that was altered was the removing of identifiable data and anonymising. I also watched the video of each interview to capture non-verbal and body language not discernible in the audio file and added these to the transcripts.

Punctuation such as commas and full stops were also used to reflect pauses in speech, sometimes creating incorrect phrasing but reflecting the cadence of the interview. The transcripts were exported to Word and each line was numbered for ease of reference.

At this point I stepped away from the research, contending with more health issues along with personal and professional ones. Although this led to a period of months away from the data, the phenomenon was never far away, always present in my lived experience and hovering in my mind. I would be on a walk or listening to music and suddenly a thought or feeling would arise that would bring a participant or sentence into focus. Moustakas (1990) highlights that it is precisely our moving away from intense concentrated focus that allows “the inner workings of the tacit dimension and intuition to continue to clarify and extend understanding on levels outside the immediate awareness.” (p.29). This process is key to the incubation stage of heuristic inquiry.

3.12. Analysis

It took a year for me to return to the data and during this year I spent a lot of time reflecting on my experience of living with and beyond CD. This deep self-inquiry illuminated new dimensions of experience, particularly around identity and time. I decided to use NVivo to review each transcript which I read several times, highlighting and ‘coding’ sections as I worked through each verbatim. The non-verbal phenomena which I had captured provided an additional layer of data as I reflected on how participants paused, took breath, how they held themselves while speaking, which allowed further immersion in the analysis. The coding process involved highlighting a passage I intuitively felt was important and pointed to something essential of the participant’s experience, then giving it a name. Although this was a lengthy process as each transcript revealed around 30-40 codes/themes, I intentionally did not spend too much time checking the importance of these passages or the accuracy in the name of the code I had chosen. My thought process was to trust my *intuition* and *tacit knowledge* to guide this step. However, when trying to move to the next stage of analysis, I experienced a strong feeling of anxiety and self-doubt that perhaps my approach, rather than intuitive, was cavalier. I began second guessing myself and the choices I made, worried that perhaps I had overestimated my ability to discern important themes. I reached out to my supervisor for guidance who reassured me that doubt was part of the heuristic process and that I should trust my intuition. I decided to set the data to one side for ‘an interval of rest’ (Moustakas, 1990) and found that when I returned to the transcripts, I removed some of the themes, selecting only the quotes that still felt evocative.

I exported these quotes and codes/themes to a Word document, one for each participant, and printed these out. I proceeded to make notes in the margin of the theme to denote which dimension of experience I felt this theme spoke to: Physical, Social, Psychological, Spiritual, or Temporal. This proved challenging as I recognised certain quotes could speak to themes across multiple dimensions, which reflects the relational and interconnected quality of the layers of experience. As van Deurzen (2015b) states, “we should not imagine that the four worlds model is an actual representation of how the world is organised. It is not a map. It is merely a structural heuristic device” (p.78). Given that we are beings-in-time, most themes touched on temporality, however I chose to assign themes that spoke specifically to the participant’s relationship with time under this relational layer. At this stage, I returned to the individual transcripts to check that the themes identified and mapped qualities essential to each participant’s experience. Two participants had also provided additional materials in the form of diary entries and videos, and these served to further immerse myself in their accounts. Once I felt I held clear individual depictions, I referred to the essential themes identified in the pilot study to consider whether the themes from my co-researchers reflected the same qualities or constituted new themes. By holding the pilot themes as my frame of reference, I considered whether participant themes were referring to different sides of the same coin or something completely different. This stage was marked by intense periods of *indwelling* as I was mindful of not wanting to try and force the data to fit together.

I found that many of the essential qualities of my co-researchers’ experiences echoed my own. However, I did identify three new themes and renamed two of the themes to capture the broader experience. For example, changing the theme *Finding meaning* identified in the pilot analysis to *The quest for meaning*, reflected the seeking and journey of meaning-making in CD. I then sent the gathered themes to my supervisor for review, who highlighted that several of the theme names were descriptive but lacking in nuance. For example, the theme ‘Being towards the body’ failed to capture the emotional feeling behind the experience, which was mostly negative. I took this feedback on board but felt that keeping the theme name broad captured that the experience of CD in the physical dimension is not just about developing negative feelings towards the body, but also becoming more aware of it and how different it feels. We agreed that these nuances pointed to sub-themes within the experience. I proceeded to *focus* on each dimension to identify further sub-themes.

Before moving to the stage of *explication* by writing up the findings, I decided to create individual portraits of each participant to vividly capture their experience. Moustakas (1990) suggests choosing 2-3 depictions that exemplify the group, but I felt I wanted to create individual portraits of each participant as each had something unique that spoke to both their individual experience and the phenomenon of living with and beyond CD. Rather than creating something in my own words, I decided to use my co-researchers' words as a way to honour their voices. I sat with each page of printed quotes, and selected passages that vividly brought the co-researcher to mind. Then came the process of arranging the quotes into a poem that felt evocative and aesthetic. I sat with each collection of quotes, moving words around to create a flow without losing the essence of experience. This took time as there were moments where it felt as though the words were there but not the feeling. I moved back and forth with each, reading portions aloud until something in me felt moved. Once I had created a poem for each participant, I read them out in turn which stirred something in me. At that moment, I felt I had managed to capture each participant but wondered whether they would agree. I emailed each co-researcher their poem and ask for any feedback and whether this still felt in line with their experience since it had been 18 months since the interviews. I felt apprehensive waiting for their replies, worried I had failed to accurately depict their experience. When every co-researcher came back with positive feedback and confirmation that their poem did indeed capture their experience, I felt immense relief. I also returned to my own poem, which was now almost three years after interview, and experienced the same stirring of emotions – confirmation that this was still the portrait of my experience of CD.

When I reached the stage of *explication* and creating the Findings chapter, I experienced another episode of intense self-doubt. Trying to create the narrative to present each theme under the five dimensions felt challenging as I could see all the overlap as the boundaries between the dimensions blurred. I knew that experience could not be compartmentalised and that therefore choosing to present my findings in this way would be demanding, but I also came to realise through conversations with my supervisor and personal therapist that the self-doubt I was experiencing was not due to the fact that experience is difficult to map across the dimensions, but rather that I was worried I would ‘do it wrong’. I could feel this immense pressure on my shoulders to get things right, whatever that meant. It took my therapist reminding me that I was now the expert on this topic to push past the mental block. I had to acknowledge that not only had I been living with and beyond Cushing’s disease for almost 14 years, but I had also undertaken an in-depth research project which meant I could speak to the data.

The final step in heuristic research is to produce a *creative synthesis*. Moustakas (1990) suggests this may take the form of “a poem, story, drawing, painting, or by some other creative form.” (p.32). To me, the creative synthesis should not only convey the phenomenon but also the process and journey of the researcher. Consequently, this doctoral thesis is my creative synthesis. It is punctuated by poems, journal entries, images, and all the data I have collected in my quest to explore the experience of Living with and beyond Cushing’s disease. The following Findings chapter presents individual depictions along with the essential themes of the CD experience.

4. Findings

The findings chapter has been divided into two main sections. The first part contains individual depictions in the form of poems demonstrating the unique facets of each experience, and further includes demographics of each participant. The second part brings together participants' accounts in a composite depiction of living with and beyond Cushing's disease, presenting the themes and sub-themes that have emerged from the verbatims under each dimension of existence: physical, social, psychological, and spiritual, with the added temporal dimension. The chapter concludes with a summary of key findings and sets the scene for the following discussion chapter.

Part 1 - Individual depictions

Poems were created for each participant using quotes taken from their verbatim transcript. I chose to use direct quotes to maintain the participants voices and create aesthetic and powerful accounts of their individual experiences. Rare disease patients often report experiences of feeling unheard and unseen (see section 2.8.), using participant's own words is therefore a deliberate act to counter the lack of lived experience representation in Cushing's disease and rare disease research in general.

Direct quotes have only been altered to remove filler words such as "um" or repeated words, and words have been added in square brackets to clarify meaning. No changes alter the intent/meaning behind each quote, and each poem was reviewed and approved by the participants.

Participant demographics and profiles

I have presented in the table below the participant demographics collected. There are noted differences in disease presentation across gender (see section 2.9.2.) however, my study only included women. Following my pilot interviews, I became aware of the importance of the temporal dimension and reflected on the impact of time on lived experience. I recruited participants that were more than two years since diagnosis to ensure ethical practice and this is discussed in further detail in the methodology chapter. I also chose to record time since diagnosis and time between diagnosis and intervention of all participants to include objective time measure to the subjective experiences of temporality shared. Given that Quality of Life studies highlight impact on work life (see section 2.9.4.), I also chose to collect information on employment status. Finally, I recorded details of any intervention or treatment undergone to observe differences across the group however I (Stephanie) was the only participant who suffered a recurrence and underwent more than one treatment intervention.

Table 1
Participant demographics

Name/Pseudonym	**Gender (self-identified)**	**Approximate age at diagnosis**	**Time between diagnosis and treatment**	**Interventions**	**Time since diagnosis at interview**	**Employment status**
Chloe	Female	Late 30s	Several months	Transphenoidal surgery	3 years	Employed
Ellie	Female	Early 30s	Several months	Transphenoidal surgery	4 years	Unable to work due to disability
Joyce	Female	Early 60s	2 years	Transphenoidal surgery, removal of pituitary gland	9 years	Self-employed
Kate	Female	Early 50s	Several months	Transphenoidal surgery	4 years	Employed
Stephanie	Female	Mid 20s	1 year	Multiple transphenoidal surgeries, removal of pituitary gland	10 years	Employed
Vivien	Female	Late 40s	Several months	Transphenoidal surgery	4 years	Unable to work due to disability

Chloe

I was at my wit’s end
When you say Cushing’s, nobody really knows
You feel a bit of a freak
[They say] ‘We didn’t see it at the time, you were just Chloe’.

I don’t know how I would ever have survived this without my faith, without my church family
It was my faith that carried me through
Saw me through the darkest of nights and the hardest of times
Having come out the other side, I can see his hand moving through all of it
The God that I believe in is real and he really is looking out for me

It’s good to talk. It reminded me of how far I’ve come
If I can get through that and survive that then I can do this.
It’s made me a stronger person, a more confident person.

Part of me wants people to realise that you do still live with it afterwards
They never say that you’re cured of Cushing’s, they only ever say that you’re in remission
It’s still that niggling in the back of your mind that it might come back
Every little thing, is this Cushing’s coming back again?

Part of me wants to feel like I'm normal.
And then there's a being reminded you're not and you do have to be sensible about things.
Things take you by surprise don't they in your life?

Some months I think I’ve cracked it and other months we’re back to square one
Something out of the blue comes up and you’re suddenly faced with it.

Ellie

She was listening but not listening.
But then Who am I to say? I'm not medically trained.
I felt very vulnerable and very open being this size
I was feeling that my body was morphing into something that wasn't my body.
They say they understand but how can I expect them to understand unless they're living it?

Part of me said, Oh, I'm going to be fine. And I wasn't!
After surgery, I felt mentally I was cracking.
I had lost so much of my independence
If I allow myself to really feel this, I will just crumble
The hardest things for Cushing's patients is the psychological emotional impact it has

So much has changed in my life, so much of my independence has been lost
So much because of Cushing's
Everything comes back to: because of Cushing's
It will always be part of me in all aspects of conversations
because it's such an important part of me right now
even though sometimes I just wish I didn't have to talk about it, it's my life.

There is that ever presence of it
Knowing that Cushing's is always there
Is this going to be my identity for the rest of my life?
Because I don't even say 'I used to have' Cushing's
I'm very much still there.

Where does this person now fit in society?
What am I then if I can't work
Where do I now fit in?
Maybe there is a bit of a mark, a space for me somewhere
I've also learned so much about myself
It's also given me the meaning of life, of appreciating as hard as it can be sometimes, that I’ve been given a second chance

Joyce

My appearance made for stress.
When I wasn't working, I was resting.
And life's too short to be resting all the time.
You're meant to be experiencing things and I wasn't living, I really wasn't living.
I felt that my life was draining away
I really felt that my life force was evaporating, and I thought, I'm dying.

I knew that I knew more than my GP knew. Because I'm in my body.
It's not good enough to treat each thing as a separate issue.
Just look at me as a whole being.
I'm dying, and you don't know what it is.
And I don't know what it is.
And they might know what it is.

Once I had the diagnosis, I don't think I was afraid. I just knew that I would be alright.
I've always regarded myself as fairly robust mentally.
[But] I just need some support, I need it to be acknowledged.
We all have difficult thoughts don't we?
If we don't acknowledge them as part of ourselves, then it becomes a secret.

I know what it's like to be not heard.
Who speaks up for the people that can't speak up?

I don't think you move on. I think that you assimilate the experiences.
I guess it's part of a narrative of who I am
Because what I'm remembering now as I talk to you is how limiting it was in terms of my physical ability.

There was a loss of independence there.
Some days when I'm walking, I really feel connected
Other days, I'm dragging my feet
These are the two extremes.

There's nothing I can do about the fact that I don't have a pituitary,
or the fact that I have to take 20 milligrams of hydrocortisone every day,
there's nothing I can do about that.
But that doesn't mean to say that I have to be helpless.

Kate

‘Yes I'm having really bad mood swings’ I said, ‘that's one of the reasons I gave up my job’.
And that was it.
They asked me the question, wrote it down, and that was it.

I couldn't even breathe hardly, I was out of breath all the time.
And nobody was listening.
Nobody seemed to care.
I couldn't be bothered to go to the doctors anymore with the rejection.

You get what you're given in life.
There's not really much we can do about it.
We're given these things for a reason, maybe we've been given it to help people push along.
Maybe I was given this because I'd wished it upon myself.

I didn't want anybody to see me. I didn't want any photographs.
I couldn't even walk past a shop window and look at myself.
I felt humiliated with myself.

I can't go on like this. I'm not me anymore.
I don't even feel the same way.
I just didn't even think I loved anybody anymore.
It was like this coldness in my heart, there's nothing there.
It's kind of robbed me of my feelings.
Give me back.... me.
I just want me back again.

My expectations were that I was gonna have the surgery, lose weight immediately
And get back to being myself again
I thought, I'll be fine. I'm strong. I can get through anything me.
But this has definitely knocked me for six.
I honestly think that I needed counselling afterwards.

I'm thankful that I haven't got Cushing's anymore.
But I wish I'd never had it because I think it is a lifelong disease.
No matter where you are, or what you're doing, it's there. It's always there.

It's always there in the back of your mind.
From when it first starts to get to you,
and then you go through it
and then you end up living with it afterwards as well,
even though it's not there.

No one thinks about the person that's been there and gone through it.
‘Oh you've come out the other side, you're fine now’.
No I'm not fine. I'm still going through it. I'm still not me.

When you talk about it, you can get it over and done with pretty quickly.
But, when you realise how many years that's taken up of your life...

Stephanie

I remember feeling so young…
What I was projecting into the world was not who I was.
I didn't feel like me, because I didn't look like me,
and I hated looking in the mirror.

I felt isolated because no one understood what I was going through.
If I reached the end of the day and felt exhausted,
I expected to wake up the next day with a new reserve of energy.
But that wasn't a given for me anymore.

They never told me what to expect.
My expectation was to slim back down to who I was before,
as if nothing happened…

In hospital and medical surroundings, I felt like I was being abused.
Yet they were the only places I felt safe.
I didn't really have much choice.
The choice was, do this or die.
But I wanted, I needed more.

I guess I should just be grateful that I survived Cushing's.
So what if I have memory issues and am a bit slower on the uptake?
But it's not so what…
If all these things are gone, what am I left with?
I have something which make me rare and unique and different.
And I hate it.

This is not okay, I am not okay.

Vivien

I had voices screaming in my head.
And I thought, I'm going to die.
And I couldn't tell you why.

She was the first person,
The first doctor who I'd seen in three years, who actually treated me like an individual,
As a human being rather than a nutty idiot.

Having been initially upset, it was like, okay, it's either this or you die.
Let's get on with it.
They put me to sleep before my operation, and I had all the screaming.
When I woke up, it was all quiet, it was lovely!
So, I know that's exactly what it was.

I've got different friends from different walks of life.
With each of my friends, I would say a little about what was happening with me
They'd say, without saying it, we're not interested.
Because we're so rare,
They don't want to know.

Unless I'm actually talking to somebody who has had Cushing's,
Nobody understands.
Because it's not for everybody.
Sometimes you need to talk to somebody who's actually living the life.

I'm one of the quite bad ones,
because they didn't diagnose me soon enough.
I'm quite damaged.
I've been left in quite a disabled state.

I'm getting used to the idea.
But I don't quite know what's what really

Part 2 - Composite depiction

The findings are detailed further under the four dimensions of existence: physical, social, psychological, and spiritual, with the added temporal dimension. Although themes are presented under each of the headings, they are interwoven. The participant's words are presented with verbatim quotes in "speech marks", *italicized* and in purple font, with name; transcript number (if required) and line number (e.g., *Stephanie; 1.164-168*). These have only been edited for clarity by removing filler or repeated words and do not alter their intent. **Bold** text is used to show particular emphasis made by the participant. Breaks in speech are denoted with "[…]"and bracketed words mark nonverbal communication. The dimensions and main themes that sit under them, are represented below and a full table of themes and sub-themes can be found in the appendices (Appendix J).

Table 2
Table of main themes

Living with and Beyond Cushing's disease				
Physical	**Social**	**Psychological**	**Spiritual**	**Temporal**
Being towards the body	Being dismissed by medical professionals	Navigating identity	Vulnerability and choice in the face of mortality	The challenge of waiting
The complex and paradoxical expectations and experiences of recovery	Having a large part of the experience ignored	Cushing's as limit situation	The quest for meaning	Age
Letting go of normality and accepting the givens of illness	Feeling abused yet safe	Psychological distress	Beliefs	Illness enduring
	Negotiating relationships	The paradox of being that one in a million		
	Needing to connect through shared experience			
	Finally being seen and heard			

4.1. The physical dimension

The physical dimension is the world of the body. The experience in the physical dimension is represented by three main themes: **Being towards the body; The complex and paradoxical expectations and experiences of recovery**; and **Letting go of normality and accepting the givens of illness**.

The theme of **Being towards the body** encompasses the sub-themes of *Physical changes*, *Heightened awareness of the body*, and *Bodily hatred;* and expresses the attitudes and feelings developed towards the body that was changing and no longer felt comfortable. This theme highlights the self-hate that can develop when one's body becomes unrecognisable and therefore also links to the temporal dimension by underscoring changing attitudes towards a changing body, over time. Experiences in the physical dimension also link to the social and psychological dimensions as body presentation in the social world and the impact of being seen by others also impact sense of self.

The experience of recovering from treatment forms **The complex and paradoxical expectations and experiences of recovery**. This theme speaks to the complexity of a recovery process that is often fraught with unrealistic expectations about remission and cure, presented in the sub-themes of *Weight expectations*, *Expectations set by healthcare professionals,* and *Lengthy recovery*.

Finally, **Letting go of normality and accepting the givens of illness** represents coming to terms with being ill and accepting the loss of a sense of normality. 'Letting go' also involves saying goodbye to wishes and aspirations for the future, and expectations of what life should be, including the sub-themes of *Life beyond CD*, and *Rules around steroid management*.

Being towards the body

Physical changes

When asked about their experience with CD, all participants started by describing the physical changes they observed in their body as first indicators that something was wrong. Physical changes such as acne, weight gain, a red face, led to uncomfortable feelings towards the body that were central to the description of CD across the accounts of all participants. The body felt unfamiliar at times, like it was *"morphing into something that wasn't my body" (Ellie; 1.164-165)*.

Heightened awareness of the body

Along with this uncomfortable unfamiliarity and feeling of the body being different, there was a heightened awareness of bodily sensations and the limitations of the body. Stephanie described how meeting new people was an anxious experience in which she was powerfully aware of *"sweat dripping down my face" (Stephanie; 2.269)* and an overall feeling of being physically uncomfortable.

Joyce summarised physical limitations and particularly how much she felt a loss of independence. She described how at times she felt that she was dying, *"I felt that bad" (Joyce; 321)*. Joyce also expressed finding her change in appearance *"hard to cope with" (Joyce; 623)*, leading to a sense of embarrassment in which *"my appearance made for stress." (Joyce; 139)*. This sense of embarrassment was echoed by Chloe: *"Because you're just such an odd shape. [...] you'd feel quite a bit of a freak." (Chloe; 816-819)* and Kate, who disliked her new appearance so much: *"I didn't even take photographs of myself because I didn't (short pause) I didn't want anybody to see me." (Kate; 1744-1745).*

Bodily hatred

Stephanie's feelings towards her changed body turned to hate. *"I hated it so much because, because I hated myself, I hated how I looked." (Stephanie; 1.555)* This self-hatred led to a turning away from her reflection and a feeling of discordance between the image she projected *"into the world" (Stephanie; 1.556)* and her sense of self. This negative sentiment towards the body was shared by others including Kate who described how she would punish herself for what she interpreted as a personal failure *"I felt humiliated with myself. I was blaming me, I used to punch myself in the stomach." (Kate; 200).*

The complex and paradoxical expectations and experiences of recovery

Weight expectations

Descriptions of the recovery process following surgical removal of the pituitary tumour began for all with acknowledging unrealistic expectations held about what recovery looked like. One of the biggest expectations was around losing weight. Several participants mentioned not only expecting to lose weight immediately after surgery, but also that shedding this excess weight would somehow reverse the course of CD. Stephanie shared *“my expectation was [...] you just slim back down to who you were before and it’s as if almost nothing happened.” (Stephanie; 1.165-168).*

This belief around weight loss and reversal of the condition was not only held by the participants but also present and reinforced in the CD community. Speaking about conversations within online support groups, Kate shared how recently diagnosed people would look to transphenoidal surgery as a magic cure, but her own experienced showed her that *“Never! (laughing) That's never gonna happen.” (Kate; 1351)*

Even for participants who immediately lost weight, the results following treatment did not meet expectations. Vivien expressed anger for being in a position where she needed to lose weight, stating *“it’s me getting rid of stuff that shouldn't have been there in the first place.” (Vivien; 937-938)*. One of the paradoxical points of recovery is that your biomarkers may come down, meaning from a medical perspective you are cured of CD, but the lived experience suggests you are still ill. Ellie shared that the challenge for her was underestimating how much of a struggle recovery would be as it brought with it new symptoms *“I suffered tremendously with chronic fatigue and chronic pain constantly” (Ellie; 1.606-607).*

Expectations set by healthcare professionals

In fact, recovery proved to be challenging for several participants due to expectations regarding the recovery process set by healthcare professionals. For Joyce, she was told surgical intervention would lead to better quality of life, which meant she suffered in silence. *“And when somebody says you'll feel great and you don't feel great. It's hard to say isn’t it?” (Joyce; 406).*

Stephanie was warned recovery would likely be painful and arduous but was told this was a good sign: *“So in a way I wanted that for myself. [...] Because I wanted that to show me that I was cured.” (Stephanie; 1.188-190).* So painful recovery was seen as a test Stephanie needed to pass in order to *“come out the other end feeling like myself again.” (Stephanie; 1.201)* However Stephanie’s suffering continued for quite some time as she suffered a recurrence and: *“when it came back round the second time, everything was so much harder and so much more painful (tearful).” (Stephanie; 1.459-460).*

Lengthy recovery

A protracted recovery process was experienced by all participants who spoke of the challenges they faced several months and years later despite being considered in remission from CD. Kate reflected how at the time of interview, four years after surgery, she was still experiencing all over body aches, which suggested her 80-year-old mother was *"probably in better health than me!" (Kate; 1269)*. For Ellie, the continued experience of pain and limitation made her question *"actually, am I getting better?" (Ellie; 1.611).*

Joyce described the ongoing and paradoxical process of recovery as:

> *"some days when I'm walking and I walk a lot, I really feel connected. I feel, I don't know, I feel vibrant. [...] You know, I'm alive. Other days, I'm dragging my feet. [...] But that's, these are the two extremes." (Joyce; 564-567)*

Letting go of normality and accepting the givens of illness

All participants were left steroid dependent, as is common following transphenoidal surgery for CD. So, although all participants were considered in remission from CD, they were left having to come to terms with a new condition requiring medical management. Vivien's account of recovery and remission highlights the challenges that remain beyond intervention: *"I've been left in quite a disabled state. And, I'm getting used to the idea. But, I don't quite know, what's what really." (Vivien; 723-724)*

For Stephanie who experienced a recurrence and therefore had to undergo complete removal of her pituitary gland, speaking of the moment she was told she was in complete hormone deficiency she shared *"that's when I realised I was never gonna be cured, or I was never gonna be normal again." (Stephanie; 1.807-808)*. She compared the difference between health/normality and illness as:

> *"I knew that when I went to sleep I would wake up, and I would start with a new reserve of energy. [...] But that's not a given for me anymore. [...] I think it's the one thing that people who have never experienced a chronic condition, or an acute life changing condition can't understand. (Stephanie; 2.604-612).*

Life beyond CD

This theme of coming to terms with life beyond CD as a learning process, was echoed by other participants. For Chloe, this process looked like having fleeting moments of forgetting she now had a different serious medical condition. *"It's like, I've got a medical bracelet kind of thing that I wear. And you know, there are times where I think, oh I don't really need that. (laughs)" (Chloe; 945-946).* But when reflecting on the ramifications of forgetting about taking extra steroids or not wearing a medical alert bracelet, Chloe described this as *"quite a sobering thought really." (Chloe; 1009).* These moments of needing to stress dose and take extra hydrocortisone to manage a stressful situation served as a reminder to Chloe that she was no longer normal. *"I guess that is part of that, you know, part of me wants to feel like I'm normal. And then, there's a being reminded, well you're not, and you do have to be sensible about things." (Chloe; 968-970).*

Rules around steroid management

In fact, several participants spoke about how confusing rules around stress dosing and hydrocortisone management were. For Ellie *"it's just the unpredictability, I guess, with the hormones. So I don't know if they'll balance out, I don't know how to control them sometimes." (Ellie; 2.173-175)*. Joyce expressed curiosity around being instructed to take hydrocortisone at set times of the day, yet no explanation being given as to how to manage clocks moving forward or backwards. And Joyce's experience of set rules around hydrocortisone management contrasted Chloe's experience:

> *"trying to get the balance right with the hydrocortisone had been a lot of trial and error. And again, the endo was kind of like, 'Well, you know how you feel' kind of thing. 'So play around with it a little bit' like, which isn't very reassuring really. (laughs) It would be nice if somebody said, well take this dose at this time, and you'll be fine. But, that's not the nature of it is it?" (Chloe; 259-263).*

In fact, trying to manage how to meet the demands of everyday life with hydrocortisone was described as a confusing endeavour: *"Some months I think I've cracked it and other months... (chuckles) We're back to square one kind of thing." (Chloe; 285)*

4.2. The social dimension

The social dimension is the world of relationships. This world is full of challenges and tensions including navigating relationships with medical professionals, friends, and romantic partners. This dimension is portrayed by six themes: **Being dismissed by medical professionals; Having a large part of the experience ignored; Feeling abused yet safe; Negotiating relationships**; **Needing to connect through shared experience;** and **Finally being seen and heard**.

The theme **Being dismissed by medical professionals** encompasses the sub-themes of *Not being heard,* and *Facing assumptions*, and highlights healthcare professionals' tendency to focus solely on the body and not view the person as a whole. Medical professionals failed to see the person behind the diagnosis and underestimated the impact of Cushing's disease, perhaps due to a lack of understanding or experience with this rare condition.

Having a large part of the experience ignored meant not having treatments explained and not being involved in the decision-making process. Doctors were focusing on the disease but ignoring the illness, meaning the focus was on physiological treatment whilst the emotional and psychological impact of the condition was not attended to, as highlighted by the sub-themes *Frustrating relationships, Lack of acknowledgement, Lack of information and support, Carrying a secret, Lack of therapeutic input,* and *Impact of dependency on steroids.*

Feeling abused yet safe represents finding a sense of security in an unsafe and uncaring environment. The sub-theme *Treatment by others* also touches on the experience of verbal abuse in the social world and finding safety in the diagnosis and among medical professionals.

Negotiating relationships illustrates the challenges of forming relationships whilst never feeling fully understood or heard. This theme also highlights the experience of sharing with partners and children the added responsibility of health and emergency planning and wondering what that burden feels like. This theme encompasses the subthemes of *Family, Friendship, Partners,* and *Employers* to reflect the diversity of roles and relationships.

Needing to connect through shared experience emphasises the comfort and value found in shared experiences and building a support network, but also includes the sub-theme *Drawbacks* which highlights some of the negative consequences of over-engaging with the CD community.

Finally being seen and heard represents the relief of finally being seen and heard by those who were previously dismissing and highlights the power of recalling the experience by *Sharing my journey*.

Being dismissed by medical professionals

The social dimension is the dimension of relationships and for most participants the journey with Cushing's started with being dismissed by medical professionals. Each spoke about the ways in which their GPs would bat away their concerns. For Stephanie, when she spoke to her GP about her excessive weight gain looking for answers for this unexplainable symptom, it was met with incredulity rather than curiosity.

> *"my GP would pretty much every appointment just say to me: 'you need to exercise, you need to lose weight, you need to diet'. Always giving me things to do rather than actually trying to explore what was going on." (Stephanie; 1.7-10).*

Ellie also shared her experience of being dismissed and experiencing discrimination and assumption she was not taking care of her health enough:

> *"My GPs were saying you need to exercise, you know, indirectly, but very directly saying you're lazy, like come on, you know, get with it, this is your health! You've got to really look after yourself, you need to exercise." (Ellie; 1.172-174)*

For Kate and Joyce, the emphasis from doctors was that their issues had a psychological source rather than a physical one, despite their lived experience. Kate spoke of experiencing intense breathlessness which was a foreign feeling to her as she had always taken pride in her health *"I couldn't do anything. I couldn't even breathe hardly, I was out of breath all the time." (Kate; 585-586)* Only for her doctor to undertake a cursory examination and conclude *"'No, there's nothing wrong with you. It's all in your head'." (Kate; 543).* Kate found this amusing to reflect on considering the placement of the CD causing tumour, yet at the time, this was not amusing at all *"It's all in your head! How bloody dare she?" (Kate; 544)*. At the time, the experience of being dismissed led Kate to feel that *"nobody was listening. Nobody seemed to care." (Kate; 586)* Which meant she began to feel as though she was inconveniencing her GP *"I felt myself apologising for going to the doctors" (Kate; 224).*

Not being heard

The theme of being dismissed due to not being heard was echoed in all accounts. Joyce's doctor suggested the root cause of her symptoms was psychological and linked to life events *"he kept saying, oh, you're anxious because your husband's not well." (Joyce; 147).* But Joyce kept insisting *"That's not the problem. The problem is physical." (Joyce; 149-150)* because she felt she was managing her mental health well and felt robust mentally as she worked in mental health. Despite what Joyce was telling her GP, he kept dismissing her concerns, and this was a feeling that was familiar to Joyce as she had previously had Fibroids that had also been dismissed *"I remember that well. Because I had very heavy bleeding. And at that time, nobody had listened to me either. So I know what it's like to be not heard." (Joyce; 170-171).* Even when Joyce was finally able to be heard by a doctor to request a referral to a specialist, she had to be firm about why *"because there's something wrong with me. I'm dying, and you don't know what it is." (Joyce; 208-209)*

Facing assumptions

Ellie also described finally getting past the initial dismissal only to be met with further assumptions *"it felt like she was listening but not listening. She was listening but not listening. She had her own perceptions already of what needed to happen and what was going on with me." (Ellie; 1.299-300).* But Ellie found it hard to challenge the specialist's assumptions because multiple experiences of being dismissed and not heard led to self-doubt about her lived experience:

> *"She was explaining all this stuff to me and even though it did make sense at the time, something was still telling me No, there's something... I don't think it's that. But then I'm like Who am I to say? I'm not medically trained." (Ellie; 1.303-305).*

Being dismissed by medical professionals was not an experience contained in the pre-diagnosis stages of the participants' CD journey. Reflecting on the appointment where her GP delivered the diagnosis, Stephanie shared how it was delivered in a very matter of fact way *"my GP was so flippant about: 'here's the diagnosis but it's the weekend so just wait'." (Stephanie; 1.99-100)* which she experienced as dismissive of the impact this diagnosis had on her. Kate shared how the unfair experience of being dismissed was repeated for many in the Cushing's community throughout the CD journey *"They've gone from this doctor that doesn't want to know, then they're going to a trainee that really, is just very dismissive." (Kate; 1696-1697).* Vivien put forward that medical professionals being dismissive was likely linked to the condition being rare and consequently doctors not wanting to take the time to understand the impact of the condition. *"even my cousins who are doctors, they don't want to know [...] their cousin's got it, so if they don't want to do it for a relative, who do they want to do it for?" (Vivien; 1650-1656).*

Stephanie's account also highlights that the experience of being dismissed extends beyond the treatment stage. In Stephanie's case, it was the side effects of treatment and the long-term impact of living with CD for so long that were dismissed. She described how her concerns around the cognitive impact of the condition were met with an attitude of *"so what" (Stephanie; 2.476).* This dismissal reinforced the difference in priorities between medical professionals and patients, whereby doctors only focus on achieving biomedical cure:

> *"it's almost like I'm being made to feel like I should just be grateful, that I survived Cushing's. [...] so what if I have some, memory issues and, so what if, I'm a bit slower on the uptake [...] But... I think to me, it's not so what?" (Stephanie; 2.472-476)*

Having a large part of the experience ignored

Being dismissed by medical professionals started with them ignoring certain parts of the CD experience. As previously mentioned, this was often ignoring physical symptoms and the participants' accounts of their lived experience. But an area that felt particularly ignored by all participants was mental health and the psychological impact of the CD journey. Ignoring the psychological needs of patients means not addressing or even acknowledging the place for psychological support.

> *"Depression, anxiety, anger issues, mood swings, all that. They're in the description, textbook description of the disease. They don't do anything about it! [...] it was just the expectation that once my physical symptoms, or once the cortisol came down, everything else would be better." (Stephanie; 1.226-229).*

Frustrating relationships

Other participants expressed frustration that the impact of CD on mental health is ignored when it is in fact one of the clinical signs and symptoms of the disease. Kate shared how she was asked about mood swings and despite expressing that her mood swings were so problematic she ended up having to leave her job, the conversation never went beyond this. *"they asked me the question, wrote it down, and that was it. It was sort of never enhanced on." (Kate; 1023-1024).* Ellie's experience with her GP was even more limited and demonstrated the lack of interest in emotional health even more acutely *"he didn't ask about my mental health. I think that's really important when they don't ask: Well how are you doing? How are you feeling?" (Ellie; 2.441-443)*.

As Ellie points out, not only is mental health a huge aspect of the CD experience, but should also be considered in every interaction from *"the medical teams and the endocrinology team, and even through to when you sit with a neurosurgeon, I think the mental health aspect is such a huge, huge thing" (Ellie; 2.419-421).*

Lack of acknowledgement

For Joyce, it should start with medical professionals recognising and acknowledging the impact hormonal conditions such as CD have on mental health and placing that on par with the physical impact rather than ignoring it or deeming it to be under another professional's purview. Because despite psychological symptoms being listed in clinical descriptions, as Joyce expressed:

> *"That's not enough is it? You know, that's giving a rhetorical nod to it, but actually, we're saying it might happen, but we're not going to talk too much about it. And I think that's, I think that's a lack, I think, in the treatment, the whole treatment process." (Joyce; 646-649)*.

Lack on information and support

Kate points out that even during aftercare, there is a lack of information and support from medical teams which lead to patient organisations and support groups having to fill the gaps. But as Kate highlights, support groups *"are brilliant. But it needs to come from the medical guys, you know. The help that, that we should be able to get afterwards. You know, talking to a psychiatrist" (Kate; 956-957)*.

The lack of acknowledgement from medical professionals regarding psychological impact could also lead patients to not wanting to acknowledge emotional difficulties and as Joyce highlighted *"if we don't acknowledge them as part of ourselves, then it becomes, it becomes a secret in a way, doesn't it?" (Joyce; 650-651)*.

Carrying a secret

Ellie's account of holding this secret alone and what happened when she finally had the space to explore underscores the impact of ignoring this part of the experience:

> *"I remember the frustration I had where I had to wait such a long time. And I felt like I was forgotten about in between that process and that I felt very alone after surgery. Oh my goodness, how do I deal with this? What's happening in my head? Am I going crazy or? You know, how do I... I'm having all these mood swings, I'm crying, I'm... I'm frustrated. I'm, who do I talk to? How do I talk about it? And I remember finally when I did get my therapy through, all that I could talk about at the time, because it was consuming my life, was my work situation, because I was right in the battle of it. So I couldn't even talk about Cushing's." (Ellie; 2.402-408)*

Stephanie shared several points in her journey where she felt she would have benefitted from psychological input to help her with decision making and also to fully consider the implications of her treatments. *"I had to make the decision, that basically was gonna impact my fertility, was gonna impact, you know just loads of things. [...] I never got to speak to anyone about that" (Stephanie; 1.745-747).* This lack of consideration by medical professionals for the psychological impact of treatment also highlighted to Stephanie that she was not really involved in decision making and that her doctors were solely focused on one outcome:

> *"I think that the discussion about whether to have treatment or not or what treatment to have, is much too short. [...] I think that all the doctors approached it as an obvious, like, well you need this to survive, this is your only chance. This is your only chance at a cure because that's the ultimate goal for them." (Stephanie; 1.1237-1242).*

Lack of therapeutic input

What is highlighted in Stephanie's story is that even when the ultimate goal of cure or remission has not been reached, medical professionals fail to consider the value of therapeutic input, despite the disappointment likely felt by everyone involved, especially Stephanie:

> *"I do remember thinking: 'why have they not offered me any psychological support?' Like, they know that I've had, two failed surgery, one that was successful but didn't last long, so essentially, three failed surgeries! I'm in my 20s. And, you know, this is* ***not*** *okay, I'm not okay!" (Stephanie; 1.754-757).*

Impact of dependency on steroids

Another area that several participants noted was ignored by medical professionals was the seriousness of being left steroid dependent following treatment. Vivien shared that it took three years following surgery to actually receive training in managing the Sick Day rules and learning to inject herself with hydrocortisone, should she go into a fatal Adrenal crisis. Joyce's experience was similar as she didn't receive any training or information initially, and by the time she did, she wasn't supplied with all the equipment necessary to keep herself safe *"I have my little adrenal pack. I carry it everywhere. But I don't have a needle, which isn't a lot of good really if it happens to me in Sainsbury's." (Joyce; 941-942).* Joyce also shared she only recently received a steroid emergency card outlining the protocol for managing an Adrenal crisis, which felt like *"the first time they have ever* *acknowledged that, you know, that was a necessity." (Joyce; 946-947).* Ellie shared that in her local ambulance service *"a lot of them hadn't either dealt with adrenal crisis or adrenal insufficient patients, Cushing's disease, or it wasn't really something that they had awareness on" (Ellie; 1.510-512)*, suggesting part of her experience was ignored through lack of awareness.

Feeling abused yet safe

A theme that emerged from Stephanie's experience but did not seem to feature in others was her experience of medical interventions and treatments feeling abusive yet experiencing a sense of safety in the environment in which the abuse happened.

Stephanie developed physical marks and scars from each intervention, and these became symbols of the trauma she experienced *"I would be black and blue. I'd be covered in bruises. [...] and would literally look like I'd been beaten up. Or abused in some way and I, that's how I felt, I felt like I'd been abused." (Stephanie; 1.483-486)*

Yet despite how abusive hospital and medical surroundings felt, *"that's the only place I felt safe (tremble in voice from holding back tears). […] Out in the world, was just a completely different story. (Stephanie; 1.495-500)*

Treatment by others

However, what did feature in all accounts was the abuse received by others, out in public. Participants spoke about being verbally abused, insulted, humiliated by strangers and close relations.

> *"strangers would be really quite nasty, because Angela and I were walking back to the car, and, you know, when I was quite big a chap who was on a building site yelled 'Oi, there's the fat family'. And I, and I just thought, 'Aren't you a sad so and so? Haven't you got anything better to think?'" (Vivien; 1010-1012)*

Several participants spoke about the comfort of being among medical professional and the relief experienced when among other CD patients or those with an understanding of CD.

> *“I think because they knew, they kind of knew straight away, obviously, by looking at me and talking to me, and you know, and going through my history and everything. But they made me feel so at ease […] I just felt so relaxed in there, the atmosphere was great, the nurses were great.” (Kate; 690-712)*

> *“Yeah, and it's just nice to know that there are some people out there who do get it and do know what it's like and appreciate the struggle.” (Chloe; 404-405)*

Negotiating relationships

Negotiating relationships was a prominent theme in the social dimension. All participants spoke about the challenges of being in relation with family, friends, partners, and employers during and beyond their CD journey.

Family

Kate shared some of the difficult dynamics that developed within her family before she was diagnosed with CD. As an only child, Kate felt all her parents’ attention was on her, and when she began to gain weight without explanation her mother remarked, *"’Good God Kate, you are getting fat’. And I went, ‘Mum, I know! There's nothing I can do about it. I've been to the doctors, and everyone just keeps saying there's nothing wrong with me’.” (Kate; 167-169)*. Being unable to point to a cause for all her physical changes, Kate felt humiliated and blamed herself. But even when Kate finally received the CD diagnosis, it was clear the blame was not only self-inflicted. Referring to her mother, Kate spoke of how *“she tried to blame me for getting the Cushing's disease. She said, ‘Oh, well, she must have brought it on herself, because none of us have ever had it’.” (Kate; 587-589).* The impact of all the physical changes, the difficult family dynamics, and the challenges of dealing with CD led Kate to feel *“I just didn't even think I loved anybody anymore. You know, any of my family. It was like... This just coldness in my heart, there's nothing there.” (Kate; 600-601)*. The coldness Kate experienced meant she withdrew from social interactions with family and others, and refrained from engaging in the social world.

Ellie’s challenges with family centred around the post-treatment experience and expectations held by others regarding her recovery. She shared having to have difficult conversations with her mother, who was her main carer, about *“the frustration of sometimes not seeing me progress in my recovery as much as people would like or want me to.” (Ellie; 1.625-626).* This sense of frustration was also felt by Ellie who found herself arguing a lot with her mother:

> *“I was taking out a lot of my frustrations with her when I couldn't do things because she was the only person that could physically see what was happening to me, whereas everyone else was kind of outside of the bubble.” (Ellie; 1.673-675)*.

But her mother being inside the bubble came with a sense of expectation that by virtue of seeing her struggles, Ellie’s mother would understand how unpredictable and frustrating the recovery process was on Ellie. Yet, as Ellie reflected, *“how can I expect them to understand unless they're living it?” (Ellie; 1.688-689)*. It also dawned on Ellie that as her carer, her mother also witnessed difficult moments that must be hard on a parent *“she was the only one that has seen me go into an adrenal crisis, and I can only imagine what that must feel like for a mum to not know what's happening” (Ellie; 1.676-677)*. As a mother herself, Chloe spoke of wanting to protect her children from the realities of living with adrenal insufficiency *“part of me I think, plays it down a little bit because I don't want to freak them out.” (Chloe; 1026).*

Chloe’s children were quite young when she was diagnosed with CD but their understanding of the condition and the steroid dependency she has been left with has increased over time. This increase in understanding also includes an increase in awareness that CD is never cured but rather in remission, and therefore has a chance of returning. Reflecting on her children’s worry that her CD may return, Chloe shares how *“they look back and they realise how sick I was with it, and I think that would be what freaks them out the most” (Chloe; 1040-1042).*

Friendships

Relationships that extended beyond the immediate family circle were described as problematic for several participants. Stephanie spoke of experiencing a sense of isolation whilst acknowledging *“partly I was doing it to myself in the sense I was isolating myself from others.” (Stephanie; 1.268).* Stephanie’s pulling away from others and isolation were driven by her experience of not feeling understood. She described finding it hard to maintain and create relationships as she felt unable to share such a large part of her life and experience. Vivien described a similar experience whereby she found that some of her friends *“they'd say, without saying it, we're not interested.” (Vivien; 1261).* Vivien described accepting not everyone in her life was open to talking about challenges of living with CD which seemed to be linked to their inability to understand or relate to her experience. She highlighted that them not understanding or not being interested meant they could not be a support circle for her so *“rather than whack my head against the wall, I would rather think, ‘Okay, well, they can't do that for me’.” (Vivien; 1270).* Her solution to this was to identify and split off her friend groups into people who she could speak to about Cushing’s and people she couldn’t.

Chloe highlighted an inherent lack of understanding of the Cushing’s experience due to the rarity of the condition. She contrasted it to the more common and well-known condition of diabetes, suggesting many had a vague understanding of what being a diabetic entailed whereas *“when you say Cushing's, nobody really knows and nobody really knows quite what you're going through when you've got it or post-surgery.” (Chloe; 326-327)*

Ellie’s experience in the world with others also felt quite challenging at first. She found herself wanting to have the conversation around Cushing’s and the impact of cortisol on the body, but not knowing how to start. However, over time she became more comfortable and confident having this conversation, and so did her mother *“she's almost become conditioned, like myself, to getting out there and having the conversation with people quite early on.” (Ellie; 2.231-232)* For Ellie, having the conversation is not just about sharing her experience, but also educating others and raising awareness for CD. Reflecting on what it was like for those on the receiving end of the conversation, Ellie commented *“it's probably quite overwhelming that that's all somebody talks about, is what they can't do or what they're struggling to do, or because there was so much adjusting.” (Ellie; 1.669-671).* Ellie also acknowledged that in addition to the impact on confidence and communication, CD had lasting physical impact, and wondering how others might see or judge her *“I think sometimes people look at me and go, you know, Gosh, she's not, like, it's been years, and she's still quite heavy, you know.” (Ellie; 2.482-484)*

Partners

Romantic relationships were also an area that brought challenges. Some of the participants were married, some were divorced or single, all touched on the impact of CD on romantic relationships.

Ellie spoke of the evolution of her previous relationship whereby at first her partner was very supportive and trying to understand Ellie's condition by doing research and asking lots of questions. This made her feel that he had an interest in her and her experience. However, Ellie shared the frustration her partner expressed with the unpredictable nature of CD recovery and life beyond CD. *"certain things that he was saying to me, you know, 'But why is it that in 2018, after surgery, you were able to do a charity walk, but now you're struggling to like, get out of bed?'" (Ellie; 1.680-681)* For Ellie, her experience of CD not only changed her appearance but also her ability to engage in a romantic and intimate relationship, which ultimately led her to conclude *"the relationship deteriorated, it didn't last. And I believe because of my journey with Cushing's as well." (Ellie; 1.656-657).* This left Ellie to wonder how she would approach new potential dating situations.

In contrast to how she described confidence in disclosing her medical history to new friends and acquaintances, Ellie described anxiety around how she would navigate disclosure when dating. She pondered whether this should be something to disclose up front:

> *"So if a guy would want to know a bit more about what Cushing's disease is, he could then do that before he decides to message me (laughs). It's quite funny how you think about these little things of, how can you kind of put it out there to pre-warn somebody?" (Ellie; 2.210-213)*.

Ellie's feeling of needing to 'pre-warn' a potential partner of her history of CD was linked to her experience of the impact of hormones on mood and mental health, and the subsequent impact on relationships. Ellie also described feeling a lack of confidence in her physical appearance due to the sequelae of CD and surgery, this led her to conclude the solution was to avoid romantic relationships altogether for some time.

The sentiment of the CD history and subsequent steroid deficiency being a burden and responsibility that had to be taken on was also reflected on by Stephanie as she shared her experiences with her partner "*I think it was within the first few months I had to actually say to him: "by the way, I'm dependent on all this medication and if anything bad happens to me, you need to call the ambulance'." (Stephanie; 1.1260-1261).* Stephanie considered the unexpected nature of needing to have this kind of conversation at such a young age, and also of the impact this had on her partner.

In contrast, when describing the time her husband broke down in tears over the thought of losing her while she was in hospital, Kate spoke of how CD *"kind of robbed me of my feelings." (Kate; 1209)*. Rather than worrying about the impact of the condition on her husband, and despite feeling love for him, Kate shared how she had no feeling on hearing about this from her daughter.

Employers

An area which was spoken about quite a bit by Ellie is the relationship with employers. Echoing her experience with her partner, Ellie described:

> *"my employers were, at the beginning like I feel sometimes with parents, with partners, with friends, very understanding, until they're actually having to sort of deal with your ups and downs, or your absences or your restrictions or limited abilities." (Ellie; 1.744-747).*

Ellie had a very poor experience whereby she was discriminated at work and pushed out, which left a lasting impression on her. *"I felt that that was probably one of my biggest knocks, was going through my loss of employment, and the lack of empathy, compassion and understanding they had towards the end." (Ellie; 1.884-886).*

Needing to connect through shared experience

One way all the participants tackled the isolation felt through the CD experience was to connect with others who had the condition. Stephanie shared how when she was first diagnosed, she searched the internet for first-person accounts and *"when I was reading other people's experience, it was like reading my own." (Stephanie; 1.155).* Through these strangers' narratives, Stephanie felt connected as she recognised so much of their experience which also validated her own. Reading about the impact of CD from a first-person perspective gave her something no medical team did/could. Vivien explained this as *"the GPs are very good at what they do. But when it comes to specialised stuff,* *sometimes you need to talk to somebody who's actually living the life" (Vivien; 1680-1682).* Kate found reassurance in speaking with other's who'd been through the same situation and whom she could relate to. For Chloe, the reassurance came from knowing there were others out there who understood what it was like and could appreciate her struggle *"the Facebook group it is helpful, you know, is good to have and to, just to be reminded that you're not the only one" (Chloe; 394-395)*. In fact, several participants shared how they created a support system of internet Cushing's friends.

Some participants also shared about attending face to face meetings, and for Chloe, this experience was *"really quite special" (Chloe; 391).*

Drawbacks

However, in addition to all the benefits of having an online CD community, Ellie shared some of the drawbacks of these interactions: *"I'm relating to other people with these experiences, but it's also making me feel worse (laughs) at the same time." (Ellie; 2.361-362).* For Ellie, remaining in what she called a *"very negative cycle"* did not allow *"space for more positive conversations to also come in." (Ellie; 2.362-364)*. Ellie countered these negative effects by recognising she needed to step away from these online environments at times. Ellie shared:

> *"you know support groups on any aspect can be a fantastic source of reassurance and things like that. But also, is that I find that especially with Cushing's, because it is a very, can be very dark and negative condition to live with, that the conversations are,* ***can be*** *really draining." (Ellie; 2.379-382)*

Finally being seen and heard

Part of the reparative aspect of connecting with others is feeling seen and heard. Vivien and Kate spoke of the times they finally felt seen by their medical professional. For Vivien who had had such a complex mental health journey, being seen by a Cushing's specialist meant *"she was the first person, the first doctor who I'd seen in three years, who actually treated me like an individual, as a human being, rather than a nutty idiot." (Vivien; 446-447).* Kate described her interactions with the endocrinology team as *"it was like a weight was lifted off my shoulders, you know, 'Yay, somebody* *actually knows!' You know, someone, someone's heard of Cushing's." (Kate; 692-693).* Once diagnosed, Kate returned to her GP who acknowledged his shortcoming:

> *"he said, 'I need to apologise', he said, 'because if I'd have taken the time, to have looked at them, in more depth, I would have seen that there were markers there to say that there was a problem.'" (Kate; 730-732)*

Chloe's experience of being seen came as a retrospective acknowledgement that her friends had not really seen what she was going through at the time.

> *"occasionally I'll post a picture on Facebook or Instagram, you know, before and after. And people are like, 'You don't even look like the same person. And yet we didn't, we didn't see it at the time, you know, you were just Chloe'." (Chloe; 354-356).*

Sharing my journey

All of the participants also shared how therapeutic the process of being interviewed for this research project was. Several participants acknowledged this was the only time they had gone through recounting their entire Cushing's journey from start to finish, which felt really good and *"also a bit of a weight off my shoulders as well" (Ellie; 2.46)*. For Chloe who had been looking forward to the interview, the experience also left her feeling quite positive about where she is on her recovery journey and about the future. Chloe remarked *"talking about it as well is therapeutic and it helps you just get your head around things and reminds you, you know, it reminded me of where-how far I've come really" (Chloe; 1094-1095).* Vivien expressed feeling exhilarated after the interview at the prospect of having contributed to this piece of research.

4.3. The psychological dimension

The psychological dimension is the world of the self. It is the dimension in which participants grappled with their identity and sense of self. This dimension is made up of four themes: **Navigating identity; Cushing's as a limit situation**; **Psychological distress**; and **The paradox of being that one in a million.**

The theme **Navigating identity** reflects on the labels we are given and that we give ourselves to define who we are. Within this exploration, we question what happens to our sense of self and identity when the benchmarks we use to define ourselves are no longer there, highlighted by the sub-themes of *Feeling robbed, Identity and physicality,* and *Identity and capability*.

Cushing's as a limit situation is about rediscovering ourselves in the wake of a major traumatic and life-changing event. This theme links to the spiritual dimension by engaging reflections on meaning and purpose, and is about questioning what we know about ourselves, coming to terms with the realities of illness, and mourning the loss of 'normality'.

Psychological distress encompasses the varying degrees of psychological distress experienced by participants and the sub-themes of *Loss and self-awareness*. While **The paradox of being that one in a million** conveys the irony of wanting to be unique yet hating it when it is not on our terms. This theme highlights some of the challenges of coming to terms with having a rare condition.

Navigating identity

The impact of CD in the psychological dimension was felt through the sense of identity each participant held. For Kate, the physical impact meant she was no longer an active, happy go lucky person, and this really challenged her sense of self. *"Oh, God. (pause) Just give me, give me back.... me. [...] I just want me back again." (Kate; 1361)*. Stephanie spoke in terms of the labels we are assigned but that we also identify with to give us a sense of identity. She questioned whether she could still hold on to a label if she no longer fit the description:

> *"so if I'm not quick, if I'm not smart, if I'm not active... If I'm not sociable, because I'm not anymore [...] if all of these things are gone, what am I left with? I think that's what I struggle with, and that's something that no, book or, blog or anything can help you deal with." (Stephanie; 2.480-484).*

Feeling robbed

Feeling robbed of so many attributes she used to identify herself with, Stephanie questioned whether she now held the label of *"the sick one? […] Or the fragile one" (Stephanie; 2.378-382)*. Joyce never identified with the label of being disabled *"but I never feel and I've never felt disabled. I've never put* *myself in that category." (Joyce; 759).* However, like the others she integrated the CD experience as part of her story: *"I guess it's part of a narrative, isn't it, of who I am" (Joyce; 701)*.

Stephanie's choice was to identify as a Cushie, which is a nickname adopted by many patients with Cushing's, and this became a large part of her identity. Even when she no longer had active CD, Stephanie struggled to let go of that label *"if I am not a Cushie anymore, then what am I? And what is it that I'm experiencing because I know that I don't feel right." (Stephanie; 2.552-553)*. Stephanie's belief at the time of interview was that because everything she experienced was *"under a Cushing's umbrella" (Stephanie; 2.820-821)*, she would always carry the Cushing's label.

Ellie also remained attached to the Cushing's label and considered it a big part of her identity. When reflecting on how connected she felt to it, she remarked:

> *"in some ways, it would be interesting to see if I can have a bit of a detachment. And I think a lot of that would have to probably come through, like maybe feeling better within myself, like losing weight, being more physically active and not having so many mobility issues or cognitive issues. I think then being able to sort of step in, a step out of this sort of Cushing's bubble, and kind of build a, maybe a slightly different identity?" (Ellie; 2.258-262).*

Identity and physicality

Ellie's reluctance to let go of the Cushing's identity was so closely tied to her physical presentation:

> *"'Hi, I'm Ellie. I, you know, I'm in remission from Cushing's disease.' [...] You know, it's like, it feels like it's still very me. I guess, because I still feel like I also look very Cushing, Cushingoid as well." (Ellie; 2.305-307)*

In fact, Ellie questioned whether Cushing's would be part of her identity for the rest of her life or whether she could rebuild an identity whereby Cushing's was a part of it but *"it's not at the forefront of everything I do or everything I'm talking about." (Ellie; 2.269).*

Ellie acknowledged how hard she found trying to let go of the Cushing's label, despite being in remission from CD and currently living with steroid deficiency which is medically referred to as secondary adrenal insufficiency or Addison's disease. Ellie never adopted the label Addison's as she could not let go of Cushing's. This meant she did not look for Addison specific resources or sought help from the Addison specific patient organisation, opting to use the pituitary focused one instead. Even when referring to wearing the medical alert bracelet for her steroid dependency, Ellie speaks of *"there are times where I do think, gosh, I wish I didn't have to wear a bracelet, and I could just have any old conversation and almost pretend like I, there's no Cushing's there, in a way." (Ellie; 2.235-237)* when in reality, the medical alert bracelet is the symbol that represents that there is no Cushing's there since steroid dependency is the opposite of Cushing's.

Identity and capability

Another big area of challenge for Ellie was not only recognising herself but having others recognise her, specifically her capabilities in a work environment. Having experienced such discrimination at work, Ellie worried about how she would be seen by a future employer and whether they would see her potential beyond the initial presentation. In her previous workplace, Ellie was known for being a multitasker and being great at client relations, now Cushing's created new limitations and Ellie worried whether anyone would take the chance on her without knowing what she was capable of. *"Other future employers, they don't know my capabilities, they don't know who Ellie is or what she was capable of doing at work." (Ellie; 2.100-102)*

Cushing's as a limit situation

For most participants, the CD journey was experienced as pivotal *"where everything changed for me, including myself." (Stephanie; 2.825)*. Stephanie's experience of this came with the realisation that *"there was just no way I was going to ever have a normal life again." (Stephanie; 1.737-738).* Kate also spoke of the changes in herself *"I'm not the same person anymore. [...] I'm not me anymore." (Kate; 1098-1093)*. Her experience was one of sadness and hopelessness:

> *"I was in the car by myself and I just sobbed my heart out. I thought, you know, that there's just, I can't go on like this. I'm not me anymore. I don't even feel the same way." (Kate; 598-600)*

> *“It's um, I don't know, it played tricks with my mind. Really, you know, to the point of... (pause) I would have just gone out and ended it all I think. You know, I was getting to the point where I just, I couldn't be bothered anymore, couldn't be bothered to go to the doctors anymore, with the rejection.” (Kate; 637-640).*

Ellie described the *“significant and big” (Ellie; 1.527)* impact of Cushing’s on her life, sense of independence and career. *“every aspect of my life that's been affected, has being affected. […] everything comes back to: because of Cushing's.” (Ellie; 2.228-241)* And with that came a sense of uncertainty about the future. When confronting her new limitations of steroid dependence and the arduous recovery, Ellie found herself mentally *“cracking” (Ellie; 1.524)* and experiencing depression.

Chloe, however, was able to reflect on her growth through the experience *“And I think if I, if I can get through that and do all of you know, survive that, then yeah, I can. It's made me a stronger person, like I say, a more confident person.” (Chloe; 766-768)*. Aside from a greater sense of self efficacy, Chloe also experienced an increase in awareness and empathy for others whom she now recognised could be experiencing something unknown and unseen.

Psychological distress

Most participants described experiencing some form of psychological distress or feeling the need for psychological support. Vivien’s experience was perhaps the most acute whereby she described *“voices screaming in my head” (Vivien; 389).* Not only did Vivien experience psychological distress, she also did not receive any support from her GP who focused on her weight, getting to a point where she no longer felt able to look after her young daughter *“I just rang my sister and I said to her, ‘Look, I don't feel very well, can you just take Angela?’. And then I sectioned myself, because I was just feeling absolutely nutty.” (Vivien; 207-208).* It took three years of psychiatric hospital stays for Vivien to finally receive her Cushing’s diagnosis, and during this time she was placed on very strong anti-psychotic medication. But when Vivien finally underwent treatment for CD, she described *“They put me to sleep before my operation, and I had all the screaming. When I woke up, it was all quiet, it was lovely! So, I know that it... That's exactly what it was.” (Vivien; 393-394).*

Although no other participant described requiring acute psychiatric input, Joyce spoke about the need for the medical teams to acknowledge: *“that you will have these bonkers thoughts” (Joyce; 637)*. For Joyce, despite these thoughts being *“okay. Because that's just your hormones talking.” (Joyce; 638)*, she expressed feeling these weren’t the kind of thoughts she could share with her family. This was perhaps linked to her perception of herself as someone *“robust mentally” (Joyce; 630)*.

Loss and self-awareness

Chloe described changes in her ability to concentrate and her memory. These changes, in addition to physical changes, led to Chloe feeling down about herself and having lowered self-esteem. Ellie also spoke about the changes in her abilities which led to a real sense of loss *“I kind of mourn that past, that you know, of those abilities that I used to sort of have.” (Ellie; 1.848-849)*. Ellie also described heightened worry and anxiety since Cushing’s and struggling with the unpredictability of mood swings. However, her self-awareness allowed Ellie to recognise when she was experiencing low moments triggered by hormone fluctuations, and this meant she could communicate this to those around her. Nevertheless, Ellie described the psychological and emotional impact of Cushing’s as *“one of the hardest things […] something that's been the most consistent thing throughout my recovery is that, is the psychological impact” (Ellie; 1.987-990)*, not only on her but also on the relationships around her. For Kate, there was an acknowledgement that she needed counselling after surgery, but this was never discussed or suggested as part of aftercare, and Kate did not know where to turn to for this. All she was offered was anti-depressants.

The paradox of being that one in a million

Stephanie spoke about the unfairness of being diagnosed with such a rare condition and for her treatments to fail multiple times. She spoke of how being diagnosed with a rare condition differentiated her as an individual and made her feel unique, yet she resented this uniqueness and the lack of understanding surrounding it.

> *“We all want to be recognised as being individuals, as being different. So in some way, we want that through uniqueness, that specialness, that rarity. […] And yet, this is something I*

have which does make me rare and unique and different. And I hate it." (Stephanie; 2.790-794)

4.4. The spiritual dimension

The spiritual dimension is the world of beliefs, values, and ideas. The experience in this dimension is represented by three themes: **Vulnerability and choice in the face of mortality; The quest for meaning;** and **Beliefs**.

Vulnerability and choice in the face of mortality represents having to make difficult choices due to the threat of mortality, and feeling like sometimes there is no choice. In this theme, participants express fearing their fragility whilst also accepting their being-towards-death, as highlighted by sub-themes *Threat of adrenal crisis* and *Value of life*.

The quest for meaning represents a striving to fight against the futility of the illness experience by searching for and finding meaning and value in the journey. This encompasses sub-themes of *Why me?* and *Purpose.*

Beliefs encompasses beliefs around what caused the condition and the level of control or agency each participant feels they have towards the condition, presented under sub-themes of *Agency* and *Faith and God.*

Vulnerability and choice in the face of mortality

Most participants spoke about confronting their mortality at some point in their journey. Both Joyce and Vivien spoke about feeling as though they were dying leading up to the CD diagnosis. For Joyce, the experience was one of *"I felt that my, that my life was draining away. […] I really felt that my life force was kind of evaporating, and I thought, I'm dying." (Joyce; 157-159)* There was a realisation that because of all the limitations of the condition, Joyce *"really wasn't living" (Joyce, 330).* Vivien's experience of feeling as though she was dying with CD, meant that the decision to undergo surgery was seen as *"it's either this or, you die." (Vivien; 1468)* This was echoed in Stephanie's account whereby she described not feeling as though resilience was a choice *"'but what was my alternative?'. […] Because to me, what it felt like was the choice of do this or die." (Stephanie; 1.1161-1165)*

Threat of adrenal crisis

Vulnerability and mortality also became prominent themes after treatment as several participants spoke about the dangers of adrenal crises. For Chloe, adrenal insufficiency felt more bearable to live with than Cushing's but there remained a fear of having a crisis and knowing how to respond. Having had a bad experience during an adrenal crisis, Stephanie shared *"So knowing that, even a cold could potentially kill me, that terrifies me!" (Stephanie; 1.1334-1335)*. This led Stephanie to reflect on the implications of her adrenal insufficiency and to remark: *"being awakened to my own mortality and... […] vulnerability. […] and the reality of my life versus... For example my husband's." (Stephanie; 2.903-907).* And this vulnerability was felt in many areas of her life, including family planning because she was informed having children would put her health at risk due to her steroid dependency. Stephanie also recognised she might not live a long life as she had expected *"I don't know if I'm gonna make it past, 65 for example." (Stephanie; 2.909)*

Value of life

On the other hand, Ellie's experience of facing her mortality led to a positive realisation of the value of life: *"But then I've also learned so much about myself, and I think I've appreciated life a lot more with the possibility of the risks of losing your life when, you know, adrenal crisis and things like that." (Ellie; 2.237-239)*

The quest for meaning

Several participants engaged in a search for meaning from the experience of having CD.

Why me?

For some, this involved looking for the meaning of why they had developed Cushing's in the first place. Kate reasoned that the question should not be why me, but rather why not me?

> *"these things are there, and someone's gonna get them, regardless of who it is. Somebody's gonna get them. They're never gonna go away. Like cancer is never going to go away. Cushing's is never going to go away." (Kate; 1504-1506).*

However, she continued to wonder why she had been *“chosen” (Kate; 1595).* Was it due to her lifestyle choices, or *“maybe I was given this because, I'd wished it upon myself.” (Kate; 1549)*? Regardless of where Cushing’s had come from, Kate maintained the belief that *“We, we're given these things for a reason” (Kate; 1502)* and Kate continued to wrestle with the reason or purpose for why she had developed it.

Purpose

Stephanie felt determined to find meaning to her experience, as a way to counter the sense of futility of it all:

> *“Maybe there was something about like giving meaning to what I'd gone through like, that it was, you know I'd gone through all of this and it wasn't just gonna be for nothing it was gonna be to share it with other people that are going through it, to just support, and things like that.” (Stephanie; 1.339-342)*

Reflecting on her decision not to take a break from her studies while undergoing surgery, Stephanie remarked: *“Why didn't I just take some time off? [...] I was just stubborn. Because I just thought, I am not gonna let this ruin everything. [...] it was just like I had to prove something, to myself and to everyone.” (Stephanie; 1.1129-1133)* The quest for meaning became a need, which gave Stephanie’s life purpose.

Ellie framed her experience as an opportunity to re-evaluate her life and choices:

> *“But it's also given me the meaning of life, of actually appreciating as hard as it can be sometimes, that you've been given the second chance to maybe do things a little bit differently, and reassess, and refocus on what's important and what I would like to achieve or learn or study again, or try and do.” (Ellie; 2.468-471).*

Like Stephanie, Ellie chose to draw on her Cushing’s experience to support others with chronic health conditions and raise awareness for the unique challenges of conditions like CD. Being able to contribute to the CD and chronic conditions communities began to feel like a calling and a way to make her mark on the world and find her place within it.

By contrast, Vivien did not see her CD experience as an opportunity or a push to purpose, but rather *“I think it's just something that's just happened to me, you know?” (Vivien; 1380)*

Beliefs

Agency

Several participants shared their beliefs around agency and responsibility. Joyce acknowledged that there were many aspects she could not control such as her need to take regular hydrocortisone due to her lack of pituitary. However, Joyce felt there were other ways she could influence her health and manage her cortisol:

> *“that doesn't mean to say that I have to be helpless. You know, there are other things that I can do, I can eat well, I can exercise, I can look after myself, I can engage, you know, with other aspects of life. That's what I mean by being fortunate.” (Joyce; 774-776).*

Her belief was that there were lifestyle factors that influenced her cortisol levels which she could manage.

Faith and God

Chloe reflected on her journey and acknowledged the central importance of her faith and belief in God:

> *“But having come out of the other side, and looking back and reading those journals, and I'm like, wow, you can I can see what I would call, you know, his hand, you know, moving through all of it kind of thing.” (Chloe; 572-574)*.

Chloe’s belief in God was strengthened throughout her CD journey and she attributes her recovery to this strong belief *“I would say it was my faith, really, that carried me through and saw me through to the darkest of nights, and the hardest of times.” (Chloe; 562-563).* Chloe’s journey and her sharing of it has also encouraged those around her to reflect on their capacity to endure difficulties and the role of faith and God in resilience and survivorship.

4.5. The temporal dimension

The temporal dimension centralises our relationship with time throughout the illness journey. The narratives contrast ‘time’ as a general concept, from their experiences of temporality and their own timeline. The three main themes in time are: **The challenge of waiting**; **Age**; and **Illness enduring**.

The challenge of waiting presses pause on everything in life while one is undergoing testing. During this difficult period, participants felt as though time was stretching and dragging on as they waited for the results that would determine the rest of their life as captured by the sub-theme *Subjective experience of time*.

Age, represents the struggle in coming to terms with the juxtaposition of being young and sick in a place where only the old were sick. The theme of **Illness enduring** speaks to the persisting quality of illness, it demonstrates that illness is not a discreet experience that happens in a vacuum. Even many years after treatment, the effects of illness are still present in many areas of life, and one cannot pinpoint exactly where illness ends particularly under the threat of recurrence, which is presented in the sub-theme *Perpetual possibility of recurrence.*

The challenge of waiting

The experience of time, particularly when waiting for results or to receive the diagnosis, was described as particularly challenging for several participants. For Stephanie, the period leading up to diagnosis was experienced as intensely anxiety provoking but also as a period punctuated by tests and cycles of waiting in between.

Subjective experience of time

During these six to eight months, Stephanie’s concept and measure of time was marked by interventions and results rather than dates. Kate reflected on how quickly she could summarise this part of her journey, and yet her lived experience of it was a lengthy one: “*When I, when you talk about it, you can sort of you can get it over and done with pretty quickly. But, when you realise how many years that's taken up of your life...” (Kate; 528-529).* For Chloe, this waiting for a diagnosis felt threatening. As each day and month passed by, Chloe feared for her health and future:

> *“Anyway, like I say, it kind of spiralled out of control from that point on, from sort of October onwards. And it got to the February and I'd had another appointment with my endo and I was absolutely at my wit's end because I was like, ‘I'm going to end up in a wheelchair in no time at this rate’, and I can't. I've got four children, the youngest is two, and I can't afford to (chuckles) to be in a wheelchair.” (Chloe; 142-146)*

Age

The experience of being diagnosed in her 20’s felt particularly challenging for Stephanie because there was a sense of disbelief about being unwell at such a young age:

> *“I remember at the time feeling so out of place because I was 26 and everyone around me was like in the 70s because it’s a specialist hospital for neurology and neurosurgery a lot of patients there tend to be older, and have different types of surgeries. So I just felt, I remember feeling, so young. I mean I was young, but I really felt so young.” (Stephanie; 1.120-124).*

Being surrounded by other patients who were much older reminded Stephanie how unfair this felt.

One of the side effects of being diagnosed and treated young meant Stephanie was pushed into menopause and her chances of having children were significantly reduced. This aspect of Stephanie’s experience was shared by Ellie who was diagnosed in her mid 30s, but all other participants were older and had already had children when diagnosed. Stephanie felt such an early diagnosis therefore threatened her longevity but also limited her future. However, Kate, who was diagnosed in her 50s, felt being older was a disadvantage as she was already experiencing changes due to menopause and aging:

> *“Personally, I think the younger you are, the better you are at healing. [...] I think the older you are, you like, you're getting to that age where things are changing anyway.” (Kate; 1335-1340)*

Illness enduring

A key finding in the temporal dimension is that contrary to medical professional opinion that considers the condition in remission once cortisol levels come down, for the participants, Cushing’s was seen as an illness that endured. Most participants remarked on its lasting impact such as describing it as *“the gift that keeps on giving” (Stephanie; 2.811).* For Ellie, it was difficult to detach from the identity of having Cushing’s because she still felt in the cycle of recovery. Not feeling as though she was completely rid of all Cushing’s related symptoms meant she still very much experienced the disease as present:

> *“But there is that ever presence of it still very much being, it feels like still very much, that's my being of it, still at the moment. Because I just don't feel as much of a progression away from it to make me feel that like my language is starting to change when I talk about it or that I don't even talk about it at all because it's like, you know, it's a thing of the past, you know, it's not what my life is at the moment.” (Ellie; 2.346-348).*

Perpetual possibility of recurrence

For Chloe and Kate, Cushing’s endured through the threat of its return.

> *“Because I think part of me wants people to realise that actually, you do still live with it afterwards, you know, there is still, like I said, it's still that niggling in the back of your mind that it might come back. And I want people to realise that. You know, that, yeah, I'm not cured, and that I do still have to live with the adrenal insufficiency and things like that. You know, that Cushing's isn't, it isn't nice, and it sticks around. (laughs) You know, I want, I think I just want people to realise the severity of it really, and the impact that it has on your whole life, you know?” (Chloe; 856-861)*.

The worry of CD returning was always on Chloe’s mind, and despite recognising the disease of Cushing’s was no longer present, Kate still described it as *“a lifelong disease” (Kate; 1294)* because *“you end up living with it afterwards as well, even though it’s not there.” (Kate; 1299)*. As highlighted by Stephanie *“although what I'm left with now is not technically Cushing's, to me it's a continuation of the Cushing's.” (Stephanie; 2.526-527).*

Kate’s experience of Cushing’s enduring was also around feeling as though she was still going through CD as she had not returned to her previous self. This was echoed in Stephanie’s account:

“Having Cushing's and then not having it, to me is almost like a myth.” (Stephanie; 2.497). She questioned: *“where is that line between, I **have** and I **had** Cushing's?” (Stephanie; 2.692-693)*. For Joyce, this meant she could not close the chapter on her CD experience *“I don't think you move on. I think that, you know, you assimilate the experiences.” (Joyce; 440-441)*.

4.6. Conclusion

The experience of living with and beyond Cushing’s disease (CD) can be plotted along five spatiotemporal dimensions of existence: physical, social, psychological, spiritual, and temporal. The themes identified in each dimension are interlinked and highlight the multidimensional impact of the lived experience of CD.

The physical world is the dimension of the body and our relationship to the natural world. Living with CD means experiencing physical changes that affect self-image and lead to a loss of independence. The now unfamiliar and uncomfortable body also leads to an increased awareness of body-as-object and brings up feelings of self-hate. Recovering from pituitary surgery is consequently a complex and paradoxical experience due to unrealistic expectations held about weight loss and returning to a pre-disease state which are reinforced by healthcare professionals. Living beyond treatment for CD therefore means letting go of the idea of living a ‘normal’ life and coming to terms with the givens of illness such as changed appearance, changed capacities, and steroid dependency.

The social dimension is the world of relationships embedded in social, cultural, and political contexts. Living with and beyond CD means experiencing dismissal from medical professionals and having the psychological impact of the condition along with the severity of steroid dependency ignored. Relationships must also be negotiated as contrasting experiences of abuse and safety are both felt within medical environments and in the world with others. Lack of understanding and support from family, friends, and loved ones leads to a sense of isolation and withdrawal that is countered through connection with other CD patients and rare experiences of feeling seen and heard feel incredibly therapeutic. The psychological world is the personal dimension of thoughts, feelings, identity, and selfhood but links closely to the social and physical dimensions as changes in the physical and social realms challenge one’s sense of self and forces a confrontation of personal limitations. In the psychological dimension, identity with and beyond CD must be navigated and experiences of psychological distress vary but are common yet rarely attended to and lead to feelings of loss.

In the spiritual dimension of meaning, values, and beliefs, living with and beyond CD leads to a confrontation of the realities of life with illness including vulnerability in the face of mortality. Value and purpose in life is explored against a backdrop of constant threat in the form of adrenal crisis, and a search for meaning in the CD experience may challenge beliefs about agency and freedom. Living with and beyond CD also leads to temporal disruption whereby the passing of time is threatening, and future feels uncertain. One’s personal timeline and projects may be linked to chronological age yet do not abide by objective measures of time. The enduring experience of CD and fear of recurrence also leads to a subjective experience of the phenomenon as something inhabiting simultaneously past, present, and future.

The following chapter locates the findings within the context of existing literature and discusses contributions as well as limitations of the research.

5. Discussion

The following chapter is comprised of six sections that place the research in the broader literature context. The first section summarises the findings under each dimension of existence and links these to existing literature, highlighting the ways in which this study supports or challenges previous findings. The next section (5.2.) presents limitations of the study, followed by a reflexive discussion (5.3.) with my thoughts on the process of undertaking a heuristic inquiry into a phenomenon of which I have direct lived experience. After this follows a discussion (5.4.) on the implications of the study for clinical practice in both psychology and broader healthcare practices. The chapter is concluded with an outline of my dissemination plans (5.5.), and suggestions for future research (5.6.).

5.1. Discussion on the findings

The aim of this research was to undertake an exploratory study on the experience of living with and beyond Cushing’s disease (CD). Six participants (including the researcher) were interviewed using the four worlds model as a heuristic tool (van Deurzen, 2015b). The four worlds or dimensions of human experience are interrelated and represent the ontological givens of existence: physical, social, psychological, and spiritual; and provide a framework for the exploration of experience (van Deurzen, 2015). The physical world is the dimension of the biological and encompasses our relationship towards the natural world. The social world is the dimension of relationships with others, which are necessarily embedded in social, cultural, and political contexts. The psychological world is the personal dimension of thoughts, feelings, identity, and selfhood. The spiritual world is the dimension of meaning, values, and beliefs. Temporality permeates each of the four dimensions of existence and is central to the experience of living with and beyond CD, however the analysis of verbatims revealed temporal themes of experience that could be plotted within the framework under an added temporal dimension (see section 3.7.).

The findings are presented and discussed through the main themes that have emerged in each dimension of existence, with the added Temporal dimension. All dimensions of existence are intertwined, therefore the choice to present these separately is for clarity rather than implying a hierarchical or unidimensional experience. Verbatim quotes are presented in quotation marks, *italicised* in *purple font* with participant; transcript number and line numbers in parentheses; for example *(Ellie; 1.164-165)*.

5.1.1. The physical dimension

The physical dimension is the world of the body and our relationship to the natural world. The themes in the physical dimension also link to experiences in the social and psychological worlds whereby the embodied experience of CD impacts relationships with others and self.

Being towards the body

CD leads to many physical changes/symptoms caused by excess cortisol including weight gain and central obesity, acne, skin thinning and easy bruising, muscle weakness, and a rounded face (S. T. Sharma et al., 2015). Each participant account began by describing the physical changes they noticed as indicators that something was wrong. Not only did participants notice their body change in unexpected and unexplainable ways, this also led to a feeling of body unfamiliarity and relating to body-as-object (Toombs, 1992a). Toombs (1993) uses the term metamorphosis to describe the change that occurs when the healthy body morphs to the diseased body and it is interesting that this is the same terminology used by one participant: *"morphing into something that wasn't my body" (Ellie; 1.164-165)*.

The heightened awareness of bodily sensations and physical limitations experienced by participants led to an uncanny experience whereby the body no longer felt familiar and safe (Madeira et al., 2020). For one participant, this meant feeling as though she was dying. Despite many studies listing the physical impact of living with CD (Andela, Scharloo, et al., 2015; Badia et al., 2014; Broersen, Andela, et al., 2019; Crespo et al., 2013; Huguet et al., 2015; Keskin et al., 2018; Knoble et al., 2018; Lobatto et al., 2018; Nelson et al., 2013; Webb et al., 2008), only qualitative studies such as this one and those outlined in the literature review (Armstrong & Fachnie, 1991; Gotch, 1994; Graffigna et al., 2020; King, 2003) have elucidated the lived experience of these symptoms, the changing relationship towards the body, and the distress caused by appearance changes.

Findings under the sub-theme *Bodily hatred* identified feelings of hate towards the body and self-blame. This is broadly acknowledged in studies measuring body image perception and disturbances

(Alcalar et al., 2013; A. Sharma et al., 2018) however what this study adds is nuance and context to the findings of lowered body satisfaction. Both Alcalar et al. and Sharma et al.'s studies frame body image and satisfaction issues within the individual, whereas this study's findings also highlight social and relational aspects of body image. Participants shared not wanting to be seen and feeling as though their body was a source of humiliation due to changes such as weight gain. When illness leads to body changes that do not match up to cultural ideals and therefore project a negative body image, Toombs (1992b) suggests these are interpreted as negative projections of self. For one participant, humiliation was linked to a sense of personal failing and self-blame, which may be tied into societal values around autonomy and control (Baron, 1992) but also speak to social and psychological experiences since we gain our sense of self through what is reflected by others. This finding of self-blame is therefore new but not unexpected and can also be plotted in the social realm. According to Boss, "even weight loss and weight gain are fundamentally never merely a phenomenon of the physical body (Körper). They are always also an event of the human body (Leib), and as such are defined by transformed world-relation." (Boss cited in Moss, 1992, p. 278). Identifying the impact of physical changes from CD on the relationship between self, body, and others highlights the value of exploratory research that captures rich subjective data.

The complex and paradoxical expectations and experiences of recovery

Participants held unrealistic expectations about recovery following treatment, particularly around losing weight, and reversing the course of the disease. Expectations were that surgical removal of the tumour would be a magic cure: *"my expectation was [...] you just slim back down to who you were before and it's as if almost nothing happened." (Stephanie; 1.165-168).* This finding was not unexpected as it had been previously reported by King (2003) who also found participants believed the removal of the tumour would get them back to who they were before. However, the fact that these findings are still present in a study conducted 20 years later suggests beliefs around treatment and recovery have not changed. Similar findings around expectations of recovery were also found by Simpson and colleagues (2014) in their study of several pituitary conditions suggesting this is not just tied to the CD experience but perhaps speaks to broader issues.

One of these issues could be around beliefs of illness as something temporary and contained, which is reinforced by medical terminology using the word ‘cure’. Being cured of a condition implies the removal of all symptoms and sequelae of disease, which in the case of CD is not the reality. The paradoxical experience of recovery in CD is that participants were told they were cured on a biochemical level (meaning their cortisol was either within or under normal range) but still felt ill and looked Cushingoid, which was interpreted as not being cured. This is consistent with Carluccio and colleagues’ (2015) findings that patient’s self-assessed cure status was often in discordance with their biochemical status. Hinojosa-Amaya and colleagues (2021) highlight that CD literature is moving away from the term cure towards remission to reflect the likelihood of recurrence, but this may also serve to temper expectations about the curative power of treatment.

Participants shared that beliefs around recovery were not only reinforced in the CD community, but also by healthcare professionals. Acree and colleagues (2021) found similar findings that suggest doctors and patients conceptualise recovery in different ways, consequently doctors do not provide information that adequately manages expectations held by patients about recovery. Several studies also found that doctors underestimate recovery time following surgery and the presence of continuing issues (Acree et al., 2021; Valassi et al., 2022). Given doctors may underestimate and inadequately inform patients about recovery, the findings from this study are not unexpected however they do highlight the consequences of this which is that patients may withhold parts of their experience: *“And when somebody says you'll feel great and you don't feel great. It's hard to say isn’t it?” (Joyce; 406).* Or may question their experience: *“actually am I, am I getting better?” (Ellie; 1.611).* They may also not feel prepared for the possibility of recurrence. Gotch (1994) found that patients who experienced fatigue and were unable to lose weight gained due to CS considered themselves unrecovered from the condition, which echoes the findings of this study. However, given that in their global study of 320 CS patients Valassi and colleague (2022) found that almost 90% of patients reported ongoing symptoms of fatigue and obesity, you must wonder how many patients consider themselves fully recovered.

Another paradoxical element of recovery from CD treatment is that it brings new symptoms of chronic pain and fatigue, and participants described it as a lengthy and non-linear process which may have been overlooked in QoL studies that cannot capture non-linear changes (Knoble et al., 2018). As Toombs (1992b) points out, qualitative studies such as this one add value by keeping the patient voice and experience central. Previous studies have suggested ongoing physical and psychological symptoms are likely due to structural changes in the central nervous system (Brue & Castinetti, 2016; Dorn et al., 1997; Huguet et al., 2015), however this theme showcases not only the complex and paradoxical experience of recovery, but the beliefs and interactions that may contribute to it. Consequently, in line with previous studies (Alcalar et al., 2013; Van Der Klaauw et al., 2008), this study's findings suggest the importance of providing information to manage expectations.

Letting go of normality and accepting the givens of illness

In this study, every participant traded one condition for another – being in remission from CD meant taking on secondary adrenal insufficiency (SAI) which also involved getting to grips with a completely different medical condition that requires its own management. Therefore, *Letting go of normality* involved accepting that things have changed permanently because recovery isn't to pre-disease level, and *accepting the givens of illness* represents accepting the responsibility and facticity of having a new life-threatening condition that is unlikely to improve. This is a new concept as studies rarely frame recovery from CD as learning to live with SAI. This could be because studies often report adrenal insufficiency as transient, including the study by Berr and colleagues (2015) that reported 58% of patients recovered adrenal function following surgery. In this study all participants experienced enduring SAI and considered this part of their CD experience rather than a separate process. Learning to manage SAI was reported as confusing and a learning curve that received little guidance from healthcare professionals, which is in line with previous findings that patients with SAI report difficulty self-managing the condition (Li, 2022). This looked like forgetting about SAI but then remembering the severity of the condition which is *"quite a sobering thought really." (Chloe; 1009).* Literature on SAI highlights the risk of having an adrenal crisis which is the leading cause of death (Li, 2022) but forgetting about SAI was described by one participant as wanting to feel normal. This might speak to the tension van Deurzen (2015) describes in the physical dimension of the paradoxical relationship between health and illness.

Wagenmakers and colleagues (2012) found that patients with hormone deficiencies reported significantly worse energy, motivation and fatigue compared to those without, however all participants in this study were left with steroid deficiency so no comparisons could be made. One participant described herself as feeling *"left in quite a disabled state. And, you know, I'm getting used to the idea. But, you know, I don't quite know, what's what really." (Vivien; 723-724).* The concept of being disabled or having a disability has been raised in qualitative studies (King, 2003; Norman et al., 2022) but none explore the participants' relationship or identification with the term *disabled*. In this study, only two participants used the term disabled and both spoke in very different terms. One identified herself as disabled while the other denied feeling disabled and *"I've never put myself in that category." (Joyce; 759).* These are two very contrasting positions and may be linked to the social and cultural significance of being disabled. My own relationship with disability has evolved throughout this project and I have reflected on this in a further section (see section 5.3.).

Interestingly, most participants did not name (secondary) adrenal insufficiency or Addison's disease. In fact, one participant specifically spoke about not identifying with that label, choosing to define her steroid dependency as a continuation of her Cushing's experience. But given the severity of poor steroid management, it might be beneficial to frame living beyond CD as learning to live with SAI, after all, labels can allow access to more tailored information and support. For example, to access free NHS prescriptions there is a list of medical conditions that qualify with Addison's disease being listed but not Cushing's (NHS, 2023).

5.1.2. The social dimension

The social dimension is the world of relationships. This was the biggest dimension in which participants shared experiences of being dismissed, ignored, feeling abused, having to negotiate relationships, and the value of connection. Participants described the impact of their CD experience on family, friends, partners and at work.

Being dismissed by medical professionals

Studies have shown that time to CD diagnosis is around 3 years with broad variations within study and across countries (Kreitschmann-Andermahr et al., 2015; Rubinstein et al., 2020). Delay to diagnosis has been attributed to the fact that symptoms of CD overlap with other more common conditions, sometimes leading to misdiagnosis. However, what this study has found is that participants struggled to have their subjective experience taken seriously. Several participants shared going to the GP only to be told the concerns raised were likely due to poor lifestyle, suggesting assumptions were made on the doctor's part about the patients' behaviours. This finding is not unexpected given dismissal by doctors was reported by King (2003), and Norman and colleagues (2022) also found that changes in appearance that were considered indicators of illness by patients, were not interpreted as meaningful in the same way by doctors. In fact, Norman and colleagues (2022) found that many patients reported a lack of acknowledgement from medical professionals for their subjective experience, particularly when reporting vague and fluctuating symptoms which were often interpreted by doctors as somatising. In this study, one participant sought medical help for a clear physical symptom of intense breathlessness, only to be told her experience was *"all in your head" (Kate; 543)*. The findings therefore suggest delays to diagnosis were due to experiences of dismissal and doctors not listening. Hoffman (2014) cautions that pituitary disease may in fact be more common than diagnosed but that symptoms are often "mistakenly attributed to mental illness and consequently ignored or treated ineffectively, resulting in chronic, unnecessary additional suffering." (p.284).

It is worth contemplating whether experiences of dismissal might be linked to gendered experiences considering Kreitschmann-Andermahr and colleagues (2015) found men are more likely to have their symptoms recognised by doctors than women, which they attributed to the implicit bias of doctors regarding weight gain and mood swings in women that leads to dismissing or belittling of experiences. The fact that women are more likely to experience mood and depressive symptoms may also, as Hoffman (2014) suggests, likely cause symptoms to be mistakenly attributed to mental illness. Bleicken and colleagues (2010) also found in their study on Adrenal insufficiency that women's symptoms were taken less seriously by doctors than men's, and women were more likely to have their symptoms attributed to psychiatric causes. An area of research which has not been addressed in the literature review but could provide context to this theme is the concept of *epistemic injustice*. The term coined by Miranda Fricker (2007) refers to the unjust treatment or harm individuals experience in their capacity as knowers or speakers. Epistemic injustice can manifest as *Testimonial* *injustice* and *Hermeneutical injustice*. Testimonial injustice occurs when a person's testimony or contribution is unjustly discredited, ignored, or given less credibility based on their social identity, such as race, gender, age, or socioeconomic status. Hermeneutical Injustice refers to situations where individuals are unable to fully understand or make sense of their own experiences due to a lack of shared interpretive resources or social frameworks. This can occur when marginalised groups' experiences and perspectives are excluded or not acknowledged. Kidd and Carel (2017) suggest that chronically ill persons are particularly vulnerable to epistemic injustice, and I would suggest that those with rare conditions are even more so as there are no internal or external frames of reference for rare diseases as opposed to more common diseases such as cancer that have a 'public story'. A proverb taught to all new medical students says 'when you hear hoofbeats, think of horses, not zebras', and this phrase encourages doctors to think about more common and therefore potentially more likely diagnoses, rather than chasing 'zebras' – rare diseases like CD. This may explain why doctors make assumptions regarding bodily changes being attributed to lifestyle issues. However, the experience of being dismissed and not being heard by doctors also continued beyond the pre-diagnosis stage for all participants which lead to self-doubt and loss of confidence in medical professionals and highlights the continued experience of epistemic injustice. According to Charmaz (2000), "Health tends to be culturally linked to beauty, erotic attraction, and truth as well as morality, and illness and death to ugliness, grotesquerie, falsity, repulsion, and immorality." (p.60). Ill, disabled, and obese bodies are stigmatised in western society and these societal and cultural beliefs are pervasive, therefore doctors may hold implicit biases that influence their perceptions and interactions with patients who do not conform to societal norms of health and beauty.

Having a large part of the experience ignored

In addition to ignoring the physical symptoms of CD, participants felt their mental health and the psychological impact of CD was largely ignored. Despite psychological symptoms being part of the clinical description of CD and research providing evidence that these symptoms endure beyond treatment likely due to structural changes in the brain and central nervous system (Brue & Castinetti, 2016; Dorn et al., 1997; Huguet et al., 2015), most participants reported either not being asked about their mental health, or if asked, nothing being done to address their concerns. This finding is not unexpected given multiple studies (Andela, Niemeijer, et al., 2015; M. McBride, 2022) also found that the psychological and social aspects of pituitary conditions were often overlooked by medical professionals.

In line with findings by Gotch (1994), participants in this study highlighted the need for the psychological impact of the condition to be acknowledged and addressed. What this study adds to the conversation is the suggestion that mental health should be the responsibility of all medical professionals, from GP to endocrinologist and neurosurgeon. Despite NICE guidelines (2006) advocating for psychological assessment and support to be an integral part of multidisciplinary care, participants experienced a real lack of psychological input throughout the entire CD journey. For one participant, having psychologically informed conversations was particularly missed around decision making considering the life changing impact of treatment on her fertility and future life plans. Not having information and support on mental health from medical teams led participants to seek help from support groups which proved beneficial, but it was expressed that medical professionals should broach the subject and provide specialist support like speaking with a psychiatrist.

Another important area of experience that seemed to be ignored by medical professionals was the severity of SAI. It is well documented that treatment for CD can lead to hormone deficiencies (Wagenmakers et al., 2012) however what this study has highlighted is that the seriousness of this is often overlooked, as evidenced by participants sharing not receiving adequate treatment or guidelines on how to manage steroid dependency and the possibility of adrenal crisis. Given adrenal crisis is the leading cause of death for patients with adrenal insufficiency despite cortisol replacement (Li, 2022), and Broersen and colleagues (2019) found that the incidence of adrenal crisis after treatment was substantial, guidelines on adequate steroid replacement is vital for patients and medical professionals involved in their care, particularly emergency responders (P. McBride, 2013).

Feeling abused yet safe

Shapiro (2018) stresses that despite being a healing profession, medicine is filled with unintentional and often unrecognised forms of violence whereby procedures and interventions inflict pain with the goal of avoiding greater pain or death. The painful nature of medical interventions combined with the vulnerability experienced by patients in medical surroundings points to why procedures may be experienced as abusive. The theme of *Feeling abused yet safe* highlights the paradox in experiencing medical interventions as abusive yet feeling safer in medical surroundings by contrast to the cruel and abusive outside world. The safety of medical environments came from the comfort of being among professionals who had some level of awareness about CD and therefore somewhat understood the challenges participants faced. Abuse from others came in the form of judgements and humiliation, which has been captured in previous qualitative studies (King, 2003; Norman et al., 2022) but has no voice in quantitative or QoL studies.

The abusive and objectifying impact of others is reminiscent of 'the look' by Sartre. According to Sartre (1943), when someone looks at us, we become aware of ourselves as an object in the eyes of others. This experience can be uncomfortable because it objectifies us and reduces us to our physical appearance, behaviour, or other external characteristics. The look of others can also affect our self-concept and self-image as we internalise the gaze of others and adopt their perspective as our own. Consequently, experiences of verbal abuse and fatphobia from others not only speak to the social dimension of the CD experience but also link to the sub-theme of self-hate in the physical world.

Negotiating relationships

The theme of *Negotiating relationships* highlights the impact of CD on relationships and the evolution of these relationships across the course of the condition and over time. Although the impact of CD on relationships has been documented in both quantitative and qualitative studies, findings in this study also highlight the dynamic nature of the interaction as well as the impact on existing and future relationships.

Family

Negotiating family relationships included bearing the blame for having CD and managing expectations family members had regarding recovery. Participants spoke of difficult dynamics including wanting family to understand the struggles of living with and recovering from CD, whilst also wanting to protect loved ones from it, particularly children. The impact of CD on families and the fear of impact on children was also found by Gotch (1994) and is therefore not a novel finding, however one participant spoke of apathy *"I just didn't even think I loved anybody anymore. You know,* *any of my family. It was like... This just coldness in my heart, there's nothing there." (Kate; 600-601)* and withdrawal that ensued, which has not been reported previously in the context of familial relationships.

Friends and others

Participants all described friendships as challenging, predominantly due to a lack of understanding from others about their experience of CD. Existing friendships had to be reassessed and categorised into either people with whom CD could be spoken about, or people who couldn't understand or weren't interested in talking about CD; while new friendships were avoided which led to a sense of isolation. Yalom (1980) described existential isolation as an ultimate concern of human existence whereby we are aware of our ultimate aloneness, particularly in the face of suffering. Graffigna and colleagues (2020) also noted a withdrawal from social relationships which was framed within the context of stigma and lack of awareness, therefore negotiating friendships is an unsurprising finding. Leder (2016) speaks of the exiling experience of illness whereby exile from the social represents how relationships are altered. Illness can exile us from the social world through stigma, but we may also self-exile through shame (Leder, 2016). However, one participant also shared using social interactions as an opportunity to educate and raise awareness for CD which is a new finding.

Partners

Gotch (1994) along with Norman and colleagues (2022) have noted the impact of CD on romantic relationships therefore the theme of negotiating relationships with partners is unsurprising. However, the findings elucidate some of the contributing tensions including partner's loss of patience, and partner's lack of understanding for the unpredictability of the condition and for the unpredictability of the post-treatment experience. One participant also acknowledged the weight of the responsibility and burden that befalls the partner considering the risk of complications such as adrenal crisis. These findings are in line with Andela and colleagues' (2019) study on the partner's perspective that found partners experience worry regarding the severity of their ill partner's condition, along with uncertainty around how to accommodate or encourage their partner.

Previous literature focuses on the impact of CD on existing romantic relationships but does not acknowledge the impact on future ones. One participant shared anxiety around navigating potential new romantic relationships, including issues around disclosure and loss of body confidence which led her to withdraw from dating. This is a new finding in the CD literature and links to the temporal dimension by highlighting the impact of CD on the future.

Employers

Studies that have looked at the impact of CD on employment have approached the issue as something located within the patient by focusing on impaired performance at work as linked to difficulties meeting mental and physical demands and high health-related absenteeism (Valassi et al., 2011). Whilst acknowledging her ups and downs and limitations, one participant also highlighted that it was her employers lack of empathy and compassion that meant she experienced discrimination at work and ultimately was pushed out. Recognising employment issues as a social rather than psychological problem has an important significance on how the issue is addressed as one suggests it is the patient that needs 'fixing' whilst the other acknowledges that it is the relationship/context that impacts. This can be linked to models of disability whereby the medical model locates disability within the individual whereas the social model of disability posits it is the environment that is disabling. Armstrong (Armstrong & Fachnie, 1991) had full support from his employer, but no other study has looked at employment relationships, rather the focus has been on functional impact of CD on work performance (Lobatto et al., 2018).

Needing to connect through shared experience

Participants shared how reading first-person accounts of CD and connecting with other CD patients tackled feelings of isolation and provided a sense of validation and reassurance. The support provided by other people with the same condition has previously been reported in qualitative rare disease studies (von der Lippe et al., 2017), so this finding is not unexpected. However, a novel finding of this study is the drawback or paradoxical experience of engaging with other patients. One participant shared how engaging in the online CD support group too often made her feel worse by keeping her in a negative cycle of draining conversations that did not allow space for positivity. Acknowledging that peer support can also turn negative is an important finding when considering delivery of support services and interventions.

Finally being seen and heard

Linking to the theme of connecting through shared experience is the feeling of being seen and heard. Participants described moments where they finally felt seen as a whole person, including the CD diagnosis and its impact. In some instances, this involved a retrospective acknowledgement from doctors and friends of not having seen or heard before. Findings highlight the reparative aspect of feeling seen by medical professionals who acknowledge the presence of CD and their shortcomings in identifying the condition. This is a previously unreported finding in CD literature.

Participants also spoke of the present experience of feeling seen and heard during the interview process. Both King (2003) and Simpson et al. (2014) found that participants viewed the interview process in their studies as meaningful and therapeutic. In each study including this one, participants appreciated the opportunity to reflect and share the totality of their experience which has implications for both psychological and medical practice (see section 5.4.)

5.1.3. The psychological dimension

The psychological dimension is the world of the self, identity, and inner world experiences.

Navigating identity

Participants grappled with their sense of self and loss of identity due to physical changes but also changes in how they interacted with the world, highlighting the link to the social dimension. Identity was not only something participants felt they held internally but was also co-constructed through ‘the look’ of others (Sartre, 1943). This finding is in line with previous qualitative studies that have also acknowledged the role of CD and the social context in shaping and eroding identity (King, 2003; Simpson et al., 2014), however sense of self and identity is not considered in QoL measures including CD specific questionnaires (Cusimano et al., 2020; Milian et al., 2012b, 2012a; Webb et al., 2008). This theme not only highlights how participants experienced a loss of identity, but also how they reconstructed a sense of self when facing new limitations, including adopting, and attaching to the label of ‘Cushie’. Participants struggled to let go of the label and identity of being a Cushie beyond CD as everything that felt wrong or different could be traced back to CD. Never adopting the Addison’s label suggests the Cushie/Cushing’s label is hard to let go of which links to the physical dimension theme of recovery and the temporal dimension of illness enduring, and speaks to the embodied illness experience.

In their qualitative study on pituitary conditions, Norman and colleagues (2022) identified an overarching theme of ‘hidden disability’ to highlight the invisible nature of pituitary diseases and the fluctuating functional impact of the conditions. Support for use of the term is provided through three quotes including one that specifically states, “Living with a hidden disability.” (Norman et al., 2022, p. 592). The use of the term ‘disability’ has already been considered in the physical dimension however it is worth noting how it has appeared in the psychological dimension under the theme of identity. One participant stated *“but I never feel and I've never felt disabled. I've never put myself in that category.” (Joyce; 759)* suggesting disability may be an identity/label that needs to be adopted rather than something that is automatically attributed. This is considered further in the section on future research (see section 5.6.).

Cushing’s as a limit situation

The conceptualisation of Cushing’s as a limit situation is a new finding that places the experience of CD in context of existential understandings of human experience. Jaspers (1954) defined limit situations as moments that expose individuals to the ultimate boundaries and possibilities of life such as death and suffering. These moments challenge our understandings of ourselves and the world and have the potential to fundamentally change our perspective and lead to greater understanding and insight. Participants described CD as a pivotal and significant experience in their lives which pushed them to the brink of hopelessness. Pivonello and colleagues (2017) suggest patients with CD have an increased suicide risk due to high rates of major depression however the findings of this study highlight that feelings of sadness were linked to complete loss of identity and hopelessness due to repeated dismissal from doctors.

Limit situations also bring the possibility of growth and one participant spoke of how she felt stronger and more confident having ‘survived’. Her experience of CD also led to an increased sense of empathy and awareness for the possible invisible suffering of others.

Psychological distress

All participants depicted some form of psychological distress, with one describing acute experiences that led to voluntarily sectioning herself. Psychological distress is well documented in CD studies that report experiences of psychosis, mania, paranoia, anxiety, depression, and cognitive impairments to memory and concentration (Broersen, Andela, et al., 2019; Dorn et al., 1997; Tang et al., 2013) therefore this study's findings are not surprising. However, the findings highlight that experiences of psychological distress may be difficult to talk about and are not acknowledged by medical teams even though they are well documented in research. This lack of acknowledgement also meant a lack of support, as described under the social dimension theme *Having a large part of the experience ignored*.

The literature highlights that although psychological distress reduces after successful treatment, patients report not returning to pre-CD levels which is believed to be due to structural changes in the brain caused by excess cortisol (Tiemensma, Biermasz, et al., 2010; Tiemensma, Kokshoorn, et al., 2010; Van Aken et al., 2005). In this study, participants identified changes in cognition by comparing to previous abilities which brought with it a sense of loss. Given changes in cognitive ability are likely permanent, CD patients should be supported in processing this loss and finding ways to adapt to differing abilities. Indeed, experiences of psychological distress were described by participants as one of the hardest aspects of the CD experience that was also the most neglected. Unfortunately, this is echoed in the literature that reports consistent unmet psychosocial needs (Andela, Niemeijer, et al., 2015; M. McBride, 2022; Valassi et al., 2022).

A novel finding regarding experiences of psychological distress is the increase in self-awareness described by one participant that led to her ability to recognise when moments of low mood and mood swings were triggered by hormone fluctuations. This ability to recognise changes in affect due to hormones may have stemmed from previous experiences of fluctuating mood around menstruation (Sanders et al., 1983), however being able to attribute mood swings to hormone fluctuations do not lessen their impact. The topic of self-awareness around mood and hormone fluctuation warrants further research as this may have implication on how low mood in hormone conditions is managed.

The paradox of being that one in a million

In their review of qualitative studies, von der Lippe and colleagues (2017) suggest it is the patient's beliefs and feelings regarding their condition that determine their ability to cope rather than the rarity of the condition itself that is problematic. In this study, all participants spoke about some of the unique challenges of having a rare condition, whether that was delayed diagnosis, lack of awareness from friends and healthcare professionals, or having to turn to other patients as experts rather than relying on doctors; but one account specifically named the paradox of being one in a million (referring to the incidence of CD) as having something that made her feel special and unique, but that she hated. Paradoxical feelings about having a rare condition do not appear in the CD literature therefore this finding of both positive and negative feelings towards a rare diagnosis is novel and suggests there is something qualitatively different about living with a rare condition.

5.1.4. The spiritual dimension

The spiritual dimension is the world of beliefs, values, and ideas. It is the dimension in which we explore our sense of meaning and purpose, and make choices in the face of mortality. This dimension has been largely ignored in research into CD so far, with some studies mentioning the presence of spiritual concerns but not elucidating these. New spiritual themes have been uncovered however this dimension remains the least developed of the four spatial domains in this study, perhaps highlighting the challenge of exploring such a deeply personal dimension of experience. Although the conversational approach of interviews allowed for a more open exploration of spiritual themes, this relied on participants' attunement and openness towards sharing their own beliefs.

Vulnerability and choice in the face of mortality

According to Carel (2016) illness forces us to confront our mortality in a direct and demanding way. Death is another of life's ultimate concerns (Yalom, 1980) and participants confronted mortality throughout their CD experience. For two participants this was feeling as though they were dying which was linked to experiencing worsening health and increasing limitations. Symptoms of CD were associated with death and this experience was not unwarranted as CD does carry with it an increased mortality rate double that of the general population, with an estimated 5-year survival of only 50% if left untreated (Clayton et al., 2011). The experience of feeling as though they were dying led participants to frame the decision to undergo surgery as making a choice between survival and death, which ultimately did not feel like a choice. Van Deurzen (2015b) places the tension between life/death in the physical dimension however participants' experience of the perceived threat of death as a threat to freedom and choice suggests a link to the spiritual dimension of beliefs. Limitations brought on by CD leading to not feeling as though one is living also implies confronting mortality in terms of what it means to be alive which is very much the domain of spirituality.

Nevertheless, there remains a link to the physical world through the very real threat of adrenal crisis, but this is framed in the context of vulnerability and temporality – fears in the present and worries about an uncertain future. The very real threat of death due to adrenal crisis led one participant to reflect on the value of life and to learn more about herself, linking to the psychological dimension and theme of CD as limit situation. Yalom (2008) suggests that illness can be a catalyst for personal growth and self-discovery as it can serve as a wake-up call, prompting individuals to reevaluate their priorities, relationships, and values. King (2003) also reported participants reevaluating priorities and their outlook on life, but no other studies explore this existential and spiritual dimension. This could be due to beliefs about illness being framed in psychological and medical models as cognitions and therefore the domain of the psychological (Leventhal et al., 1992).

The quest for meaning

Frankl (2008) highlights the importance of finding meaning in suffering to provide a sense of purpose and help cope with the challenges of illness. Participants in this study began their quest for meaning by reflecting on why they had developed CD considering its rarity. According to Nietzsche (1895/1962) "If we have our own why in life, we shall get along with almost any how" (p. 468). For one participant, understanding the cause or origin of CD was seen as a precursor to finding meaning and purpose in the experience. Regardless of whether it was due to something viewed as controllable such as lifestyle choices, or as punishment or karma, CD was viewed by this participant as having an innate purpose, of being given for a reason. Other participants saw it as their responsibility to create a sense of meaning and purpose from the experience to counter the sense of futility it brought. Meaninglessness arises when confronting the inevitability of death (Yalom, 1980). The tension between futility and meaning is one of the paradoxes in the spiritual dimension (van Deurzen, 2015) which remains unexplored in existing CD literature, though Graffigna and colleagues (2020) identified a profound sense of insecurity in their participants which they labelled “lack of purpose and of self-efficacy” (p.150). The quest for meaning connects to the psychological dimension by linking participants’ experience of finding meaning and purpose, with how they conceptualised themselves in line with inner values, beliefs, and sense of self. One participant framed CD as having given her a ‘second chance’ to reassess and refocus her life, which echoes findings by King (2003) where participants reported CS as a meaningful experience leading to positive changes.

Several participants chose to draw on their experience to support others with CD and rare chronic conditions. This is not an unexpected finding as Armstrong (Armstrong & Fachnie, 1991) also described his belief that the experience of CS would assist in his calling to help others. This intersubjective strategy of ‘Giving-to’ is described by Leder (2022) as a patient’s way to assert that despite and because of illness limitations she can support others. Notwithstanding QoL being described as a multifaceted concept that encompasses the domain of spirituality (M. McBride et al., 2021), meaning and purpose remain unexplored themes of the CD experience in existing literature. This study’s findings suggest the quest for meaning is part of living with and beyond CD, even if the result is to frame the experience, as one participant did, as *“something that’s just happened to me” (Vivien; 1380).*

Beliefs

Participants held beliefs around what felt within their control. Agency over lifestyle choices was seen as a counter to the sense of helplessness brought on by becoming steroid dependent for one participant. Agency refers to the capacity of individuals to act as autonomous beings and make choices that shape their own lives, despite the existential challenges and uncertainties they may face. Agency therefore links to existential freedom (Yalom, 1980) and is an essential aspect of embodied experience (Merleau-Ponty, 1948/2008) but is a largely unexplored theme in CD literature.

Another previously unexplored spiritual theme that arose in this study is the role of faith and belief in God. One participant shared the central importance of her faith in carrying her through, and how her belief in God was strengthened by her CD journey. Although Leder (2016) considers the experience of illness one that exiles from the cosmos by challenging beliefs, illness can also strength religiosity (Ownsworth & Nash, 2015). Armstrong's (Armstrong & Fachnie, 1991) account also speaks of the power of spirituality: "I needed to trust in the will of my God. With that decision, I experienced a sense of peace." (p.8). Different beliefs speak to different perspectives on sense of agency and contribute to our understanding of CD as they also highlight the spiritual dimension of experience. Patients may hold religious beliefs that are significant to their experience and may therefore benefit from spiritual engagement. This was previously noted by Acree and colleagues (2021) who also highlighted that CS patients would benefit from being asked about religious or spiritual care, especially during recovery.

5.1.5. The temporal dimension

The temporal dimension was added to reflect the spatiotemporal quality of the CD experience. Literature on CD to date has neglected the temporality of experience, especially the subjective experience of time.

The challenge of waiting

The challenge of waiting as apprehended through a subjective experience of time is a novel finding. Participant accounts portrayed a subjective and embodied experience of time that was constructed through experiences rather than with objective time measures (Brough, 2001). Literature on the pre-diagnosis experience focuses on objective time measures to CD diagnosis (Kreitschmann-Andermahr et al., 2015; Rubinstein et al., 2020), however participants in this study did not focus on how much time had elapsed between first symptoms to diagnosis but rather their experience of suffering. The process of reflecting back on their time living with symptoms led to a re-apprehension of the past and a ruptured awareness of time (Svenaeus, 2011). According to Toombs (1992b), illness cannot be gauged in objective measures of time as it is a subjective temporal disruption, and this was reflected in the participants' experiences. Waiting for a diagnosis and treatment was experienced as advancing towards an uncertain and threatening future.

Age

The theme of *Age* highlights the link between the temporal and spiritual dimensions whereby my experience of having CD in my 20's challenged my beliefs and assumptions about illness and my own facticity. Being in an environment where other patients were visibly older reminded me not only of my youth (in contrast to the age of other patients), but also of the unfairness of going through this experience at such a young age. Being diagnosed and treated young also changed my life trajectory as new hormone deficiencies pushed me into menopause and took away my ability to have children. As Svenaeus (2011) describes, the future feels simultaneously mine and no longer mine as I acknowledge the loss of possibilities and choices. The theme of Age in the lived experience of CD is therefore not about objectively measured time such as chronological age, but rather about personal timeline linked to future projects.

A previous study that observed differences in experience related to participants' age, identified higher rates of depression in younger patients (Psaras et al., 2011). These higher reported levels of depression after treatment were attributed to loss of everyday functioning impacting ability to engage in working life as before. Psaras and colleagues' (2011) focus was therefore on current challenges and how these impact psychological wellbeing; and although these findings were echoed in one participant's experience with employment, the findings from the current study also highlight that younger participants experienced a sense of anticipatory loss for future plans. The future focus of participants and age as a determinant of the experience of living beyond CD could only be observed by acknowledging the temporality of illness. No other CD studies have recognised the impact of CD on individuals' experience of age, time, timeline, and future plans.

Illness enduring

The theme of illness enduring is not an unexpected finding as previous research has identified ongoing symptoms and fear of recurrence as leading to the conceptualisation of Cushing's as a complex and long-term condition (King 2003). The study by Simpson and colleagues (2014) also highlights a lack of narrative structure around boundaries of time where past and present challenges blur into one, which is echoed in this present study where one participant described "*But there is that ever presence of it still very much being, it feels like still very much, that's my being of it, still at the moment." (Ellie, 2.346).* These consistently reported findings suggest that determining when living beyond CD begins may be a highly subjective experience. The medical model suggests that patients are beyond CD when in biochemical remission, but participants experience CD as enduring which links not only to temporality but also the physical dimension and experiences of recovery. The enduring experience of CD also links to identity and the psychological dimension since participants still identified with the CD label to explain their present experience. Acknowledging that patients may consider CD an experience of the present, even after remission, has a bearing on service delivery as it suggests interventions could facilitate patients assimilating and processing their experience.

5.1.6. Conclusion

The findings in this study have highlighted that living with and beyond CD is “a complete form of existence” (Merleau-Ponty, 1948/2008, p. 110). Participant accounts provide nuance and context to the multidimensional impact of CD and highlight the temporal elements of the phenomenon. Sulu and colleagues (2022) have highlighted the tendency of endocrine research and practice to value hard data such as biochemical tests over so-called ‘soft information’, however I believe this research adds depth and perspective by keeping the subjective patient experience central. The findings of the study have revealed confrontation with existential concerns of death, isolation, freedom, and meaninglessness (Yalom, 1980) across the dimensions of the CD experience. Themes have also shown how experiences in one dimension can link to other dimensions of existence, and that temporality pervades living with and beyond CD.

This study has also elucidated several new findings previously unidentified or unexplored in CD literature, including: the impact of CD on the relationship between self, body, and world; recovery from CD involving learning to live with SAI; paradoxical experiences in the social world; the role of spirituality and faith; and the temporality of experience. A significant outcome of this research is that CD patients may benefit from multidisciplinary care that recognises and addresses the multidimensional impact of the condition which goes beyond the treatment and cure/remission stage. However, this study is not without its limitations which are discussed next.

5.2. Limitations of the study

Heuristic inquiry is a highly subjective approach that draws on the researcher's internal frame of reference; therefore, a limitation of this study is that the same data could be analysed differently. The themes and significant passages of verbatim were selected using intuition which might be subject to confirmation bias, however these were verified with co-researchers and my research supervisor. By continuously moving back and forth between the themes, quotes, and transcripts, it is hoped that the findings have stayed true to the phenomenon and that the audit trail provided for analysis clarifies the process undertaken.

The small sample size also means that the findings may not be generalisable as themes illuminate the essential characteristics of living with and beyond CD for these six participants, but it is hoped that the contribution of these findings add depth and perspective to existing literature and may speak to broader themes in CD but also rare diseases and healthcare. Significantly, the self-selected sample did not include men which is understandable give the ratio of women to men with CD however it would be interesting to find out why men did not come forward. Given observed gender differences in journey to diagnosis and presentation (Giraldi et al., 2003; Kreitschmann-Andermahr et al., 2015; Milian et al., 2014), it is reasonable to infer that men's subjective experience of CD may differ and highlight other themes, therefore this warrants further research (see section 5.6.).

Participants were recruited from a Facebook support group affiliated with The Pituitary Foundation and this may also be a limitation of the study. Individuals who engage in online support groups demonstrate a level of resourcefulness and help-seeking behaviour which includes engaging with support organisations and other patients to reduce isolation and gather information (Underwood et al., 2019; von der Lippe et al., 2017). The experience of individuals who do not or no longer engage in these groups may therefore speak to other themes in the social dimension and beyond. My own experience of online support groups has evolved throughout my journey as I initially engaged very actively but have withdrawn in the last few years. Previous qualitative studies have recruited through endocrinology services or professionals (Armstrong & Fachnie, 1991; Gotch, 1994; Graffigna et al., 2020; King, 2003) however King (2003) has highlighted that this brings limitations of its own. In the pilot stage of his study, King (2003) found that participants described their experiences by listing symptoms, complaints, and treatments, rather than describing their personal experience, requiring him to make the non-medical focus of the study and his separateness from the medical team more explicit. Recruitment of rare disease patients is often a challenge therefore working with patient organisations may be an unavoidable limitation (Griggs et al., 2009).

5.3. Reflexive discussion

What follows are further reflections on the research process including my experience of undertaking a heuristic inquiry into such a personally evocative topic.

5.3.1. Participants and recruitment

I had a feeling that recruitment would either be extremely difficult or very easy because of my previous experience recruiting for rare disease research and working within the rare disease community. What I have observed is that although a condition can be rare, therefore the potential participant pool is very small, often people are very eager to get involved and contribute to research, especially when approached through patient organisations. They are also very keen to share their experience and have their story heard which may be linked to experiences of not being heard or being dismissed, that many rare disease patients experience during the diagnostic journey (Rare Disease UK, 2018). However, despite being confident in my ability to recruit, I did not expect to have such a strong response. My ad appeared around midday on the Facebook group and within a few hours I had received 10 inquiries to participate. Of these, three were ineligible to participate as they did not meet the inclusion criteria, seven were invited to a triage telephone call and of the six participants triaged, all were found to be eligible and were invited to participate. One participant did not respond to the invitation to triage, and one withdrew before participating in the interview due to family emergency meaning a total of five participants were interviewed. With the inclusion of my experience captured in the pilot stage, a total of six accounts of living with and beyond CD were included in this study.

The presence of COVID-19 restrictions at the time of recruitment and interview may have had a positive impact on the process as online participation may have felt less onerous. Due to restrictions, all participants were confined at home and were likely familiar with online platforms such as Zoom. Ethical approval for online interviews had already been sought in anticipation of finding participants spread out geographically, consequently geographical location was not an issue though I did limit participation to UK based individuals. The rationale for this was based on the acknowledgement that different cultural contexts and healthcare systems may impact the experience of CD.

5.3.2. Demographics

All the participants included in this study identified as female. It does not appear that any men made contact based on the names of those that reached out but did not participate. This brings up questions about whether men are less likely to be in support spaces though I cannot make assumptions about whether the recruitment ad was seen by male members of the Facebook group. It may be that the advert was seen by men who chose not to express interest and it would be helpful to understand why that might be. Men's experience of living with and beyond CD may highlight different themes and challenges considering gender differences have already been acknowledged in previous studies. I also wonder whether experiences of stigma and abuse reported in the social dimension as associated with appearance changes may differ for men given the different societal expectations placed on men and women regarding physical appearance.

I collected information on treatment interventions as I wondered whether various treatments would highlight differences, however every participant had the same intervention, and it is notable that all participants described living with SAI. I did not specifically collect information on hormone deficiencies following treatment however every participant spoke of being on cortisol replacement with no other mention of hormone replacement. The main difference with my account is that I experienced a recurrence of CD and had to undergo further treatment within 2 years of my first intervention, leaving me with complete loss of pituitary hormone function. Interestingly the fact that I underwent further surgeries did not make recovery any easier because of familiarity. In fact, additional interventions felt harder and more painful, possibly because of my increasing sense of hopelessness that I would ever be rid of CD.

I collected information on ethnicity but did not present it as the results did not highlight any differences - two participants (including myself) were of mixed ethnicity and the remaining four described themselves as White British. Differences in experiences between these participants seemed to be linked to age as both participants also happened to be the youngest. Perhaps a more relevant demographic might be around culture and as all participants (except I) self-identified as British, no observations could be made. Despite being of mixed heritage and culture, I have lived in the UK for much of my life and most significantly almost all of my CD experiences including diagnosis, treatment, and recovery took place in the UK. My experience of CD is therefore also contextualised in British culture and the English healthcare system, as was the case for all other participants. As the social dimension is embedded in social, cultural, and political contexts (van Deurzen, 2010), experiences across different cultural contexts may reveal different experiences and may therefore be a point of interest for further research. For example, I am aware through interactions with other CD patients that in the United States of America, experiences of being dismissed by medical professionals can be mediated by being selective of one's choice of doctors. This is possible in the USA because there is no universal healthcare system and patients have more freedom of choice. However, the drawback to this is that in the USA, CD patients may experience extreme financial hardship due to issues with health insurance coverage.

5.3.3. Conducting heuristic research

Undertaking heuristic inquiry is an intense and demanding process. I encountered many challenges along the way linked to my choice of researching my own experience and condition, but also of undertaking research as someone who lives with chronic health conditions. The first hurdle I confronted was allowing myself to choose this topic and methodology. It took some time to accept that something I found personally important could also hold research and therapeutic value. I also feared that the centrality of my experience would be interpreted as 'navel gazing', yet how does one choose a doctoral research topic if not by also considering what holds great personal and professional importance? When my proposed research project was enthusiastically approved during the university's Programme Approval Panel Viva, I felt more confident in my decision and made good progress towards ethical approval and undertaking the pilot study. However, when I began writing up the findings from my pilot study, I struggled to find my researcher voice as distinct from my autobiographical voice. At the time it felt as though my struggle was with writing from the third person perspective about my own experience, so I chose to give myself a pseudonym. On reflection, my unease was around speaking with authority on this topic after only capturing my own data. Since working in the rare disease field and in cancer settings, I have noticed that a distinction is made between being an 'expert' and an 'expert by experience'. An expert is a professional with a lot of clinical and/or research experience in a field or topic, whereas an expert by experience draws on lived experience, and one is rarely accepted as both. This distinction borne out of how expertise is acquired is reminiscent of medicine’s tendency to value objective ‘facts’ over subjective experience, yet doctors have often shared how becoming a patient has enhanced their medical practice (Klitzman, 2008). Coming to terms with my dual position of ‘would-be knower’ and ‘knower’ and acknowledging my expertise on the topic of living with and beyond Cushing’ disease by virtue of my lived experience **and** the in-depth research I have undertaken on the subject, has not come easily. I have felt moments of intense self-doubt and ‘imposter syndrome’ – *who am I to try to speak on CD with authority*? Yet I believe it is precisely this level of questioning and self-doubt that has kept me focused on staying with the phenomenon and remaining open to my co-researcher’s experiences.

Perhaps a contributing factor to my self-doubt has also been having to contend with poor health while undertaking this project. Over the years I had moments where my level of exhaustion and mental fatigue felt so extreme that I couldn’t envisage getting to the end. A doctoral research project is a tremendous piece of work requiring sustained effort, and in those moments when I was laid in bed with a horrendous migraine, I wondered why I had voluntarily embarked on this journey. What felt most painful in those moments was that I experienced intense frustration towards the capacities I knew I had, but that now felt out of reach. I felt anger that my experience of CD was the very reason why I struggled to undertake a research project into CD. But confronting these feelings with my research supervisor and in personal therapy also helped process parts of my experience I had resisted – coming to terms with my new facticity which included reduced cognitive abilities. Confronting and accepting this part of my experience was also inevitable while engaging with existing literature. Reading about irreversible structural brain changes forced me to accept that things would never go back to the way they were before and as painful as that was, it was also liberating. It changed my relationship to the ‘Cushie’ label and allowed me to acknowledge that I was now living with disability, which has had a profound personal and professional impact. Accepting being disabled has meant I have felt able to advocate for myself and my needs. Rather than focusing on my impairments as disabling, I have challenged certain status quos, for example the long held ‘tradition’ in therapeutic practice to offer back-to-back 50-minute sessions. In the past I have felt ashamed of my difficulties with this intense work schedule until I requested the support of my line manager in changing my job plan to allow for more time in between appointments. I was able to do this because disability is a protected characteristic under the Equality Act 2010 and workplace adjustments are a legal right. Being able to shift my perspective from seeing my challenges as personal failing to framing them within the social context (i.e. moving from a medical to a social model of disability) has been lifechanging. Further research into the contribution of phenomenology and first-person perspectives on disability would prove beneficial (see section 5.6.).

5.3.4. Reflections on the interviews

The process of interviewing participants highlighted several themes, the first being how similar our experiences were. Although each participant account featured idiosyncratic qualities, the CD journey shared remarkable similarities in terms of experiencing dismissal from healthcare professionals, lack of awareness, and lack of psychological support. Engaging with each participant through the interview process, I felt a growing sense of validation that my experience had not been an isolated one but rather was shared by many. But with this realisation also came a growing feeling of sadness and disappointment for how neglected our subjective lived experiences have been in the medical space.

Another theme I noticed in the interviewing process was that with knowledge of my own experience of CD, each participant assumed when they described facets of their experience that I had an innate understanding of this. I had to consciously ensure I remained curious and open in order not to overlook any nuance or make erroneous assumptions. Adopting a phenomenological attitude was important in these moments, which highlighted similarities between unstructured research interviews and the therapeutic process. By seeking clarification and checking my understanding of the phenomenon, I could stay with each participant's account.

A final theme that emerged during the interview stage was my feelings of anger over having had CD so young. I noticed myself feeling triggered by one participant's comment that it was easier for younger people to go through CD. Her comment brought up feelings of resentment that she had lived a large proportion of her life CD-free and had been able to have children and build a life, whereas I had been robbed of a life that could have been due to experiencing symptoms from the age of 19 only to be left completely hormone deficient following treatment. Noticing this anger and defensiveness growing in me, I was very conscious of not dismissing her perspective but to try to understand it. My acute awareness of personal biases and unprocessed feelings was also an important recognition when it came to analysing and writing up the findings.

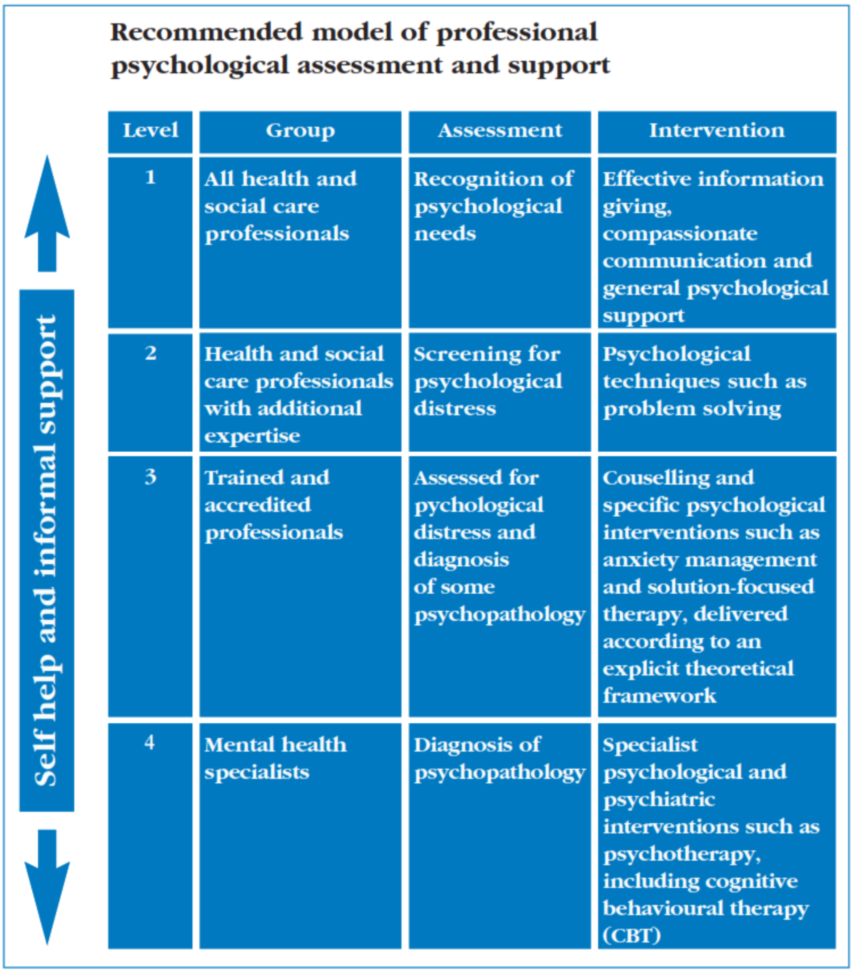
5.4. Implications for clinical practice

The findings from this study highlight several areas worthy of consideration in both medical and psychological practice. I begin by showcasing more general areas of significance relevant to all those involved in the care and support of CD patients (including doctors, nurses, and allied health professionals) before presenting specific issues in each dimension of existence and how these might be explored in psychological practice. In addition to highlighting implications of the study, I have made recommendations to tackle identified issues.

5.4.1. Implications and recommendations for all

One of the most significant findings which carries implications for all is the theme *Finally being seen and heard* which highlights the therapeutic value of having one's experience acknowledged and witnessed. Participants also shared feeling dismissed and having the psychological impact of CD ignored; therefore listening, showing interest, acknowledging experience, and if needed addressing it by signposting to support organisations or mental health professionals would be of great value. Participants believed that mental health should be everyone's responsibility and by showing interest, medical professionals demonstrate to patients that they are open to having these discussions and consider the patient's lived experience as important and of relevance. Therefore, embedding psychological services in healthcare contexts would serve to provide more holistic care and ensure lived experience remains central by acknowledging the need for psychological support in these contexts. My work in cancer services where psycho-oncology teams are embedded within wider oncology services has shown me how valuable psychological input can be and the difference it can make in patient care. Working in a systemic and multidisciplinary way means we can support patients throughout their journey, for example with difficult decision making, or to process traumatic experiences. Most cancer services strive to implement the four-level model outlined by NICE (2004) which recommends different levels of psychological intervention, but more importantly shares the responsibility across all healthcare professionals, not only mental health professionals.

Figure 6 *- Four level model of psychological support in cancer services*



Recommended model of professional psychological assessment and support

Self help and informal support

Level	Group	Assessment	Intervention
1	All health and social care professionals	Recognition of psychological needs	Effective information giving, compassionate communication and general psychological support
2	Health and social care professionals with additional expertise	Screening for psychological distress	Psychological techniques such as problem solving
3	Trained and accredited professionals	Assessed for pychological distress and diagnosis of some psychopathology	Couselling and specific psychological interventions such as anxiety management and solution-focused therapy, delivered according to an explicit theoretical framework
4	Mental health specialists	Diagnosis of psychopathology	Specialist psychological and psychiatric interventions such as psychotherapy, including cognitive behavioural therapy (CBT)

NICE (2004, p. 78)

Part of the rationale for the four-level model is “approximately half of all [cancer] patients experience levels of anxiety and depression severe enough to affect their quality of life adversely” (National Institute for Health and Care Excellence (NICE), 2004, p. 74). Given CD patients also experience high levels of psychological distress as identified in this study but also in existing literature, psychological assessment and intervention should be offered as recommended in NICE (2006) guidelines on brain tumours. The unmet psychosocial needs of CD patients are well documented (Acree et al., 2021; Andela, Niemeijer, et al., 2015; M. McBride, 2022; M. McBride et al., 2021; Valassi et al., 2022) and have also been identified in this study. The NICE guidelines on brain tumours also state:

> Patients with CNS tumours may experience psychological difficulties in adjusting to a serious, life-threatening condition in the same way as other patients with cancer. In addition, patients

> with CNS tumours frequently have cognitive and psychological problems and undergo personality changes. (2006, p. 107).

I cannot help but wonder whether the difference in service provision may be linked to the rarity of CD versus the frequency of cancer which is said to affect one in two people (*Cancer - NHS*, n.d.). In fact, more and more services supporting patients with common chronic conditions embed psychological support including oncology, maternity, cardiac rehabilitation, and chronic pain, therefore we should strive for parity of esteem between common and rare conditions. Mental health in rare diseases is a global issue (Chung et al., 2022) consequently this is not a theme unique to the CD experience but by drawing on established models in common conditions, we can strive to improve rare disease patient care worldwide.

The theme of *The complex and paradoxical experiences and expectations of recovery* also highlights the need for more information and clear communication around treatment and recovery. In recognising that patients conceptualise recovery differently and experience enduring CD symptoms, information giving and psychoeducation are key and can be provided by various professionals involved in CD care. The importance of communication in both providing information and listening (as highlighted above) also speaks to the value of creating and fostering good relationships between patients and healthcare professionals. Listening, acknowledging, and clear two-way communication are important to ensure collaborative and supportive relationships that can continue over time. This is particularly important considering many CD patients will require ongoing support and interaction with healthcare professionals to manage lifelong hormone deficiencies. The theme of *Having a large part of experience ignored* suggests the severity of SAI is often underestimated and can have a huge impact, leaving patients struggling to manage their condition.

All those involved in the care and support of CD patients need to bear in mind the embodied experience of illness and consider the multidimensional impact this complex condition can have on all areas of life.

5.4.2. Implications for mental health professionals

Considering the implications of this study for psychological practice, I would like to make broad recommendations but also highlight specific challenges in each dimension of existence that may warrant particular attention. Although these recommendations are based on findings from this CD study, I believe they can cautiously and tentatively be extended to other rare and chronic conditions.

Listening out to physical complaints

As identified in this study and echoed in both CD and rare disease literature (King, 2003; von der Lippe et al., 2017), before receiving a rare diagnosis, patients may have their physical symptoms dismissed and interpreted as psychosomatic. They may therefore present to mental health services with psychological distress and physical symptoms indicative of a rare and undiagnosed condition that mental health professionals can help explore by remaining curious and open. For example, my own diagnosis finally came with the support of an eating disorders psychiatrist who listened when I expressed my suspicion of Cushing’s and included this in his report as a condition to rule out. Although psychologists, psychotherapists, and counsellors do not have the medical background of a psychiatrist, they may still be instrumental in advocating for patients with rare diseases towards medical professionals.

Considering all dimensions of experience

The findings of this study have revealed spiritual and temporal themes previously unmapped in CD literature. By exploring the experience of illness in a holistic way, mental health professionals can address the totality of experience rather than focusing solely on the biopsychosocial dimensions. A heuristic tool such as the four worlds framework outlined in van Deurzen’s (2015a) Structural Existential Analysis (SEA) for therapeutic work may serve as a helpful guide for exploration. Consideration for the temporality of illness also “allows us to note where a person is situated and moving in terms of their trajectory and project. This gives a more dynamic sense of their intentionality.” (van Deurzen, 2015b, p. 80). The findings have also revealed that living with and beyond CD presents unique challenges in each dimension of existence and these are dealt with in turn.

The physical dimension

Therapeutic work in this dimension could focus on supporting patients in coming to terms with their changed body and exploring the relationship between body, self, and world. Feelings of self-hate and self-blame should also be explored as these may impact body image. Importantly, therapists must hold in mind the embodied nature of experience.

The social dimension

The social dimension has revealed the most themes, speaking to the relational aspects of living with and beyond CD. The first major implication is the therapeutic value of providing patients with the space to share and explore their illness experience as a whole. Bearing witness and being-with by attuning to the patient's feelings may counter the sense of exile brought on by illness (Leder, 2016). Given the impact of CD on relationships including familial, friendships, and partnerships, therapists may provide a much needed safe and supportive space. Support or therapeutic groups may also be of benefit and should be facilitated by mental health professionals given the paradoxical benefits they provide. Finally, therapists should consider working systemically and in conjunction with medical professionals to ensure holistic and multidisciplinary care.

The psychological dimension

Two main themes in the psychological dimension that warrant special consideration include working with challenges around identity and sense of self, and working with enduring psychological distress that can still present sometime after biochemical cure. Patients should be supported in coming to terms with enduring symptoms and their impact on the internal psychological world.

The spiritual dimension

Mental health professionals should accompany patients as they confront the uncertainty and awareness of mortality a diagnosis of CD and SAI brings. Working in the spiritual dimension also means facilitating an exploration of patient's meaning-making around illness and life, and addressing the sense of meaninglessness that may arise. Opening conversations about spiritual and religious beliefs may also be of value.

The temporal dimension

As lived experience is temporal, patients should be supported in reflecting on the temporality of their illness experience. The findings also highlight that working with patient's subjective experience of time may involve grieving for both past and future.

Working phenomenologically with existential themes

I believe a phenomenological and existentially informed approach to the lived experience of rare and chronic conditions allows a curiosity and openness well suited to this multidimensional experience. As previously mentioned, van Deurzen's (2015a) SEA method for therapeutic work provides good phenomenological grounding for such work. Alternatively, Frankl's (2008) Logotherapy may help patients focus on their meaning-making capacities in the face of suffering. Carel (2012) has also proposed a 'toolkit' including three phenomenological steps: the phenomenological reduction, thematising illness, and reviewing one's being in the world (p.104), as a flexible tool that facilitates examination and re-evaluation of the illness experience.

Professionals practicing in different modalities may do well to still hold in mind existential concerns of death, isolation, freedom, and meaninglessness (Yalom, 1980) as they pertain to the experience of illness. Being mindful of the physical, social, psychological, spiritual, and temporal dimensions of existence and their interrelatedness ensures holistic patient-centred practice.

5.5. Dissemination plans

Dissemination is an important part of the research process as it allows the study findings to reach a broader audience but also to potentially effect change. In the case of CD, one of the challenges of this rare condition is lack of awareness for the subjective patient experience, therefore finding ways to highlight and bring central the patient voice may serve to counter this. I intend to look for opportunities to publish the findings in peer reviewed journals, but also to present the findings at conferences to bring my co-researchers' voices to life. Additionally, I intend to publish an account of my experience of conducting heuristic research as a patient-researcher to explore the challenges and contributions researchers can make by drawing on their lived experience of illness. These dissemination plans serve to distribute the research in broader academic and clinical circles, but my intent is also to make this research accessible to all. Consequently, I will share a summary of the research with the Pituitary Foundation who aided in recruitment and intend to publish a short book with a collection of portraits/vignettes of each participant. Given the therapeutic power of having one's experience validated and represented, I believe this book of evocative depictions may hold value to other CD patients and may also serve to educate healthcare professionals on the subjective experience of living with and beyond CD.

5.6. Suggestions for future research

This study has highlighted important themes in the experience of living with and beyond CD, but several areas remain unexplored.

Men's experience of living with and beyond CD and epistemic injustice

Men's subjective experience of CD may speak to different challenges given the already identified gender differences in existing literature (Giraldi et al., 2003; Milian et al., 2014; Newell-Price et al., 2006). Although recruitment aimed to target a broad and inclusive audience, no men came forward to participate therefore intentional recruitment of men to elucidate their experiences may be helpful. The concept of epistemic injustice has also been proposed as a contributor to the experiences of dismissal and having a large part of the CD experience ignored, therefore research into this phenomenon and how it pertains to the experience of CD and other rare disease may be enlightening. Given doctors hold implicit biases regarding women's experiences (Bleicken et al., 2010; Kreitschmann-Andermahr et al., 2015) men's experience of CD may also serve as ground to contextualise epistemic injustice in CD.

Illness and disability

According to Toombs, “Illness is experienced as dis-ability, the ‘inability to’ engage the world in habitual ways.” (1993, p. 225). In this study, several participants spoke of disability in very different terms and my own relationship with disability has evolved throughout the project. The link between illness and disability is beyond the scope of this study, however findings suggest disability is linked to identity as well as experience and is not a given in illness. Norman and colleagues (2022) used the term ‘hidden disability’ to describe the biopsychosocial impact of living with pituitary conditions and equate disability with impaired quality of life due to illness. If we are to take the definition of disability as held by the Equality Act 2010, “You're disabled under the Equality Act 2010 if you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities.” (GOV.UK, n.d. para. 1). This definition would suggest that all participants in this study were disabled, however they did not identify as such. Disability is often approached through two dominant models – the medical model and the social model of disability. The medical model locates disability in the individual, whilst the social model points to society as responsible for ‘disabling’ (Peckitt et al., 2013). Through the lens of the five spatiotemporal dimensions of experience outlined in this study (physical, social, psychological, spiritual, temporal), we can see that the medical model of disability focuses on experiences in the physical dimension, whilst the social model remains in the domain of the social, with both ignoring first person lived experiences of impairment/disability (Peckitt et al., 2013). A phenomenological and multidimensional exploration of the experience of disability may contribute to broader conversations linked to cultural and socio-political interpretations of illness, and further our understanding of disability.

The temporal dimension

Findings from this study highlighted temporal themes that were located in a separate but interrelated temporal dimension of existence. Although time and temporality are broadly acknowledged as essential characteristics of human experience, to my knowledge a spatiotemporal mapping of existence as an extension to the four worlds’ model has not previously been proposed. Given van Deurzen’s assertion that time “is another dimension that needs to be plotted and explored in any research or any therapy.” (2015b, p. 79), a spatiotemporal heuristic device such as the one outlined and employed in this study may have research and therapeutic value and therefore warrants further exploration.

6. Conclusion

Cushing’s disease is a rare endocrine condition in which a benign hormone secreting tumour on the pituitary gland leads to overproduction of cortisol. Excess cortisol causes multiple physical and psychological symptoms that often persist despite biochemical cure/remission. Literature on the subjective experience of Cushing’s disease focuses on the impact of the condition on Quality of Life, and qualitative first-person research on lived experience is scarce. The aim of this study was to shed light on the phenomenon of living with and beyond Cushing’s disease through an existential-phenomenological exploration of the embodied experience beyond treatment. Given the researcher’s lived experience of the phenomenon, a heuristic research approach was adopted and six participants including the researcher took part in unstructured interviews that explored the lived experience of Cushing’s disease.

A spatiotemporal framework of existence comprised of physical, social, psychological, spiritual, and temporal dimensions was utilised as heuristic device to map the experience. The findings demonstrate that Cushing’s disease is a multidimensional phenomenon felt across all five interwoven layers of human experience. In the physical world, which is the dimension of the body and our relationship to the natural world, themes highlight a changing relationship towards the body that no longer feels familiar, and the complex and paradoxical experience of recovery from treatment, including learning to live beyond CD. Themes in the social dimension of relationships demonstrate that the experience of CD is not confined within the individual/patient but is experienced and mediated through social relationships including relationships with medical professionals, loved ones, and even employers. The psychological world of participants brings themes of identity and distress and emphasises the lack of attention paid to this area of experience in clinical practice. Themes in the spiritual dimension of meaning, values, and beliefs, highlight the existential givens of death, freedom, and meaninglessness, inherent in the CD experience and how participants confronted these. Finally, the temporal world of participants revealed previously unexplored themes of temporal subjectivity highlighting the contrast between objective and subjective measures of time.

Implications of this research on medical and psychological practice are discussed and it is argued that subjective first-person accounts of illness should remain central to ensure holistic care.

Consequently, dissemination plans aim to keep the patient voice central while distributing the findings in broad clinical circles. A recommendation to embed existentially and phenomenologically informed psychological support within multidisciplinary services is made to ensure that care for Cushing's disease patients addresses the totality of the illness experience rather than focusing solely on the functional impact of disease. Psychologists and other mental health professionals are well placed to advocate for CD patients as they are able to hold the patient's totality of experience in mind, bridging the gap between medical understandings of the disease and individuals' lived experience of the illness.

> *"A physician is obligated to consider more than a diseased organ, more even than the whole man — he must view the man in his world."*
>
> (Dr Cushing, quoted in Dubois, 1965, p. 342)

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Appendix A – Sample of analysis

Notes	Quote	Transcript reference
Searching for answers, trying to understand experience and make sense of it.	But... I don't know, I think... I guess maybe there's also an element of, if I, if I am not a Cushie anymore, then what am I? And what is it that I'm experiencing because I know that I don't feel right.	2/ 551- 552/ 00:32:53
(Time?) *The experience still feels very fresh and relevant, it is not simply a memory but something that is still lived. The expression: the gift that keeps on giving is quite interesting.*	And almost, when I think... Although I know we've last, last interview we sort of, spoke about everything that happ- . And it is a lot. But when I think that my last intervention was six years ago. To me that's... Almost unbelievable. [...] Because, it still feels like only yesterday. And yet a lot has happened in those six years. But it's like... It's like, for me, and probably why I will always call myself a Cushie, is because to me Cushing's is... Is the gift that keeps on giving.	2/ 805- 811/ 00:47:23- 00:47:40
Giving meaning to suffering *This reminds me of religious beliefs about being tested and challenged. Is there also something about punishment? And I find the visual about coming out the other end like myself intriguing.*	This is supposed to be a good sign, and it felt like this is what I have to go through to then come out the other end feeling, like myself again.	1/ 200- 201/ 00:18:46
Being young *What is it about being and feeling young? Is this related to*	So in those days you're sort of lying in a hospital bed, and-and I remember at the time feeling so out of place because I was 26 and everyone around me was like in the 70s	1/ 120- 124/ 00:11:41

mortality/lifespan/expectations about health and aging?	because it’s a specialist hospital for neurology and neurosurgery a lot of patients there tend to be older, and have different types of surgeries. So I just felt, I remember feeling, so young. I mean I was young, but I really felt so young.	
Change of expectations, coming to terms with limitations and new givens, acknowledging the lack of understanding of others.	Because it was a given that, even if I reached the end of the day and I felt so exhausted because I'd, had such a busy day, I knew that when I went to sleep I would wake up, and I would start with a new reserve of energy. [...] But that's not a given for me anymore. [...] And I think it's the one thing that-that people who have never experienced a chronic condition, or even an-an-an acute life changing, um, condition can understand.	2/ 603- 612/ 00:35:54-00:36:18

Appendix B – Recruitment advert

NSPC

Middlesex
University
London

Volunteers needed for doctoral research into:

Living with and beyond Cushing's disease

Conducted by Stephanie Yin – Counselling Psychologist in training

DCPsych student: Doctorate in Counselling Psychology and Psychotherapy by Professional studies with the New School of Psychotherapy and Counselling, in partnership with Middlesex University.

Eligibility:

- If you were diagnosed with Cushing's disease 2 or more years ago;
- Regardless of whether you are now cured, in remission, or still experiencing symptoms;
- And are aged 18 or over.

You would be an excellent candidate to participate in this research, and explore with me your lived experience of Cushing's disease.

Please contact Stephanie at email: SY305@live.mdx.ac.uk or on phone number: [redacted] for more information. Your participation would involve an online video interview of approximately one hour, which can be conducted from the safety of your own home. The research project has received full ethical approval from the NSPC research ethics sub-committee.

Appendix C – Email invitation to triage

Dear XXX,

Thank you for your interest in my doctoral research project on the experience of “Living with and Beyond Cushing’s disease”. I am delighted that you are considering taking part and would love to know a bit more about you. When would you be available for a brief telephone chat so that we may discuss your participation?

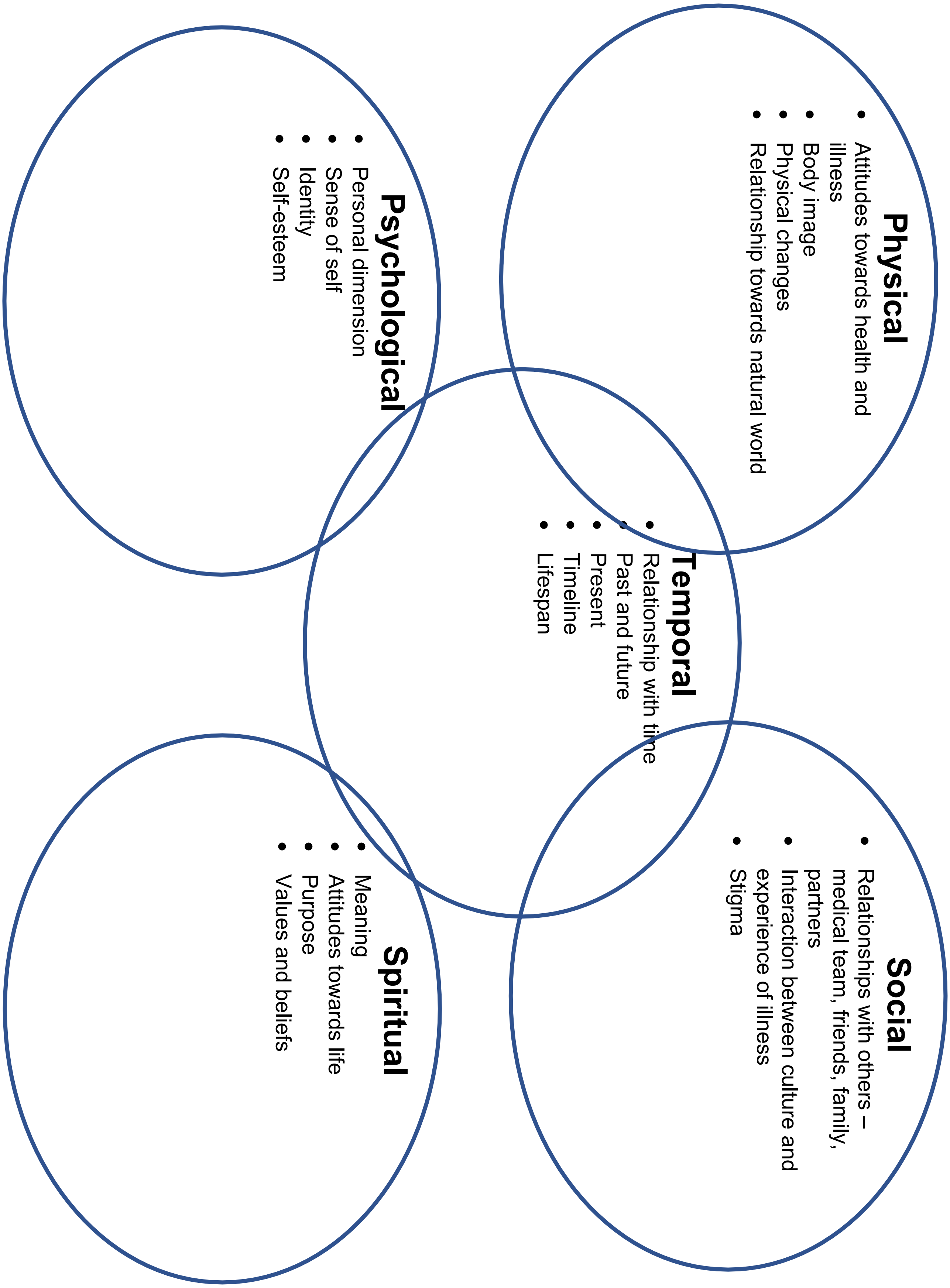
Kind Regards,

Stephanie

Appendix D – Triage crib sheet

- Can I firstly just confirm that you were diagnosed with pituitary Cushing's disease?
- Can you please tell me when you were diagnosed? (must be pre-2019)
- As this is a study on the experience of Cushing's, your participation will involve sharing your personal and possibly quite emotional journey with Cushing's, and as it can be difficult, even distressing, to talk about experiences of illness and suffering, in order to ensure your safety and wellbeing, I do need to ask you a couple of questions regarding your mental health. Are you happy for me to proceed?
- Thank you. Are you currently accessing any mental health services and/or experiencing any mental health issues (e.g. schizophrenia, bipolar, depression, anxiety, suicidal thoughts/ideation)?
    - If NO – It sounds as though you would be a great candidate for the study and I'd like to outline what participation involves – Zoom interview 60-90 mins; share journals, artwork, poems, anything you feel captures your Cushing's experience
    - If YES – What symptoms are you currently experiencing? Are these significant? Enduring? Distressing?
    - Are you receiving any treatment and what support do you have in place?
        - If suitable – invite for interview (see above)
        - If unsuitable - due to the nature of the research and the fact that the interview might be emotional, difficult, or triggering, I'm afraid you will not be able to take part in this study as the risk might be too high, outweighing any possible benefit. I'm sorry. I appreciate this may be disappointing to hear. (explore if needed) Would you like me to send you some information on resources available to you for further support?
- I would like to send you a confirmation of our Zoom interview along with a Participant information sheet for your reference, and a consent form. If you have the facilities, can you please sign and return the consent form to me? If you are unable to do so, can you please simply email back to say that you have read the consent form and agree to participate?
- Lastly, do you have any questions you would like to ask me?

Appendix E – Interview guide



Physical
- Attitudes towards health and illness
- Body image
- Physical changes
- Relationship towards natural world

Social
- Relationships with others – medical team, friends, family, partners
- Interaction between culture and experience of illness
- Stigma

Temporal
- Relationship with time
- Past and future
- Present
- Timeline
- Lifespan

Psychological
- Personal dimension
- Sense of self
- Identity
- Self-esteem

Spiritual
- Meaning
- Attitudes towards life
- Purpose
- Values and beliefs

Appendix F – Consent form

Middlesex University School of Science and Technology
Psychology Department
Written Informed Consent

Title of study and academic year: Living with and beyond Cushing's disease, 4th year.
Researcher's name: Stephanie Yin
Supervisor's name and email*: Patricia Bonnici – Admin@nspc.org.uk*

- I have understood the details of the research as explained to me by the researcher, and confirm that I have consented to act as a participant.
- I have been given contact details for the researcher in the information sheet.
- I understand that my participation is entirely voluntary, the data collected during the research will not be identifiable, and I have the right to withdraw from participating in the project at any time without any obligation to explain my reasons for doing so.
- I understand that I can ask for my data to be withdrawn from the project until data analysis.
- I further understand that the data I provide will be used as part of a doctoral research project, and subsequent publication including but not limited to psychology journals, healthcare conferences, and magazines.

______________________________ ______________________________
Print name Sign Name

Date: ___________________________

To the participant: Data may be inspected by the Chair of the Psychology Ethics panel and the Chair of the School of Science and Technology Ethics committee of Middlesex University, if required by institutional audits about the correctness of procedures. Although this would happen in strict confidentiality, please tick here if you do not wish your data to be included in audits: ___________

Appendix G – Participant information sheet

New School of Psychotherapy & Counselling
Fortune Green Road
London
NW6 1DR

The Department of Health
and Social Sciences
Middlesex University
London NW4 4BT

Living with and beyond Cushing's disease

Participant Information Sheet

Thank you for your interest in my doctoral research on the experience of living with and beyond Cushing's disease. I am conducting this research in partial fulfilment of a Doctorate in Counselling Psychology & Psychotherapy by Professional Studies with the New School of Psychotherapy and Counselling, in partnership with Middlesex University.

What is the purpose of the research?

This study wishes to gain a better understanding of the experience of Cushing's disease from the patient's perspective. You have been selected to take part in this project because you were diagnosed with Cushing's disease over 2 years ago, regardless of whether you are still experiencing any symptoms.

Do I have to take part?

No, your involvement in this project is entirely voluntary and you are free to withdraw without consequence. If you agree to take part in this study, you will be asked to sign a consent form and will be given a copy of this information sheet for your records.

What will happen to me if I take part?

You will be asked to share your experience of Cushing's disease in a face-to-face interview, or an online video interview. Face-to-face interviews will be organised in a suitable location ensuring privacy and quiet, and if you are taking part in an online interview, please ensure that you are in a private location where you will not be interrupted. Interviews will be conversational, and may take place over two encounters lasting around 60-90 minutes each. You are however free to end the interview at any time without question, should you wish to do so. All interviews will be recorded and typed up for analysis. You are also encouraged to share with the researcher personal logs, journals, poems or artwork in which you have recorded your experience, should you feel comfortable to do so.

What will happen to the data?

All identifiable data will be anonymised in order to respect your privacy, and interview transcripts will be encrypted and stored in a password protected cloud storage and on an external password protected hard drive. Only one electronic file will contain all of your details such as real name, pseudonym attributed, unique ID code, contact details, and demographics. This file will be password protected, encrypted, and stored separately, and will be destroyed on completion of the project. Physical data such as the interview tapes and personal documents will be kept in a locked safe box. Interview tapes will be destroyed on completion and personal documents returned to you or destroyed, as agreed. The use of all data arising from the interview(s) and personal documents will be limited to research and publication purposes, and the researcher will have sole access and responsibility over the data. A copy of anonymised research data will also be held by NSPC for a period of 10 years.

What are the possible disadvantages of taking part?

Please bear in mind that by talking about your experience of Cushing's disease, this may bring up some difficult feelings and memories. You will have the opportunity to discuss this with the researcher after the interview, and details of organisations which can provide further support will be provided, should you need them.

What are the possible advantages of taking part?
Sharing your experience of Cushing's disease has no direct benefit, however you may find it helpful to reflect on your own experience. The findings of this study will also help to increase the understanding of Cushing's disease from the patient's perspective.

Who is organising and funding the research?
This research is self-funded and there are no conflicts of interest to declare.

Who has reviewed the study?
All proposals for research using human participants are reviewed by an Ethics Committee before they can proceed. The NSPC research ethics sub-committee have approved this study.

If you have any further questions, please contact me:

Stephanie Yin
Tel: [redacted]
Email: SY305@live.mdx.ac.uk

If you have any concerns about the conduct of the study, you may contact my supervisors:

Dr Patricia Bonnici
NSPC Ltd
61-63 Fortune Green Rd
London NW6 1DR
Tel: 0845 557 7752
Email: Admin@nspc.org.uk

Dr Charlotte Harkness
NSPC Ltd
61-63 Fortune Green Rd
London NW6 1DR
Tel: 0845 557 7752
Email: Admin@nspc.org.uk

Appendix H – Debrief form

New School of Psychotherapy & Counselling
Fortune Green Road
London
NW6 1DR

The Department of Health
and Social Sciences
Middlesex University
London NW4 4BT

Living with and beyond Cushing's disease

Thank you for taking part in this research project on the experience of living with Cushing's disease. I value your participation and thank you for the commitment of time, energy, and effort you have given to this project.

The aim of this study is to provide a richer understanding of the experience of living with Cushing's disease from the patients' perspective, which is made up not only of the physical symptoms of disease, but also of the psychological and emotional impact this condition can have on one's life, even after treatment.

If you would like to receive a summary of the research findings once the project has been completed, or if you have any further questions regarding your participation in this study, please contact me by email SY305@live.mdx.ac.uk

Researcher: ***Stephanie Yin***
Tel: [redacted]
Email: SY305@live.mdx.ac.uk

Supervisors: ***Dr Patricia Bonnici and Dr Charlotte Harkness***
NSPC Ltd
61-63 Fortune Green Rd
London NW6 1DR
Tel: 0845 557 7752
Email: Admin@nspc.org.uk

Resources

If you would like further support, the following resources are available:

The Pituitary Foundation

UK Charity providing support and information to people affected by pituitary conditions.

Website: www.pituitary.org.uk

Patient Support and Information Helpline - 0117 370 1320
(available Monday to Friday from 10.00am to 4.00pm)

For email support: helpline@pituitary.org.uk

Text Support - 07786 202 249

Mind

Mental health charity

Website: www.mind.org.uk

Mind infoline – 0300 123 3393
(available Monday to Friday from 9.00am to 6.00pm)

Text: 86463

Samaritans

National charity providing support to anyone in distress

Website: www.samaritans.org

Helpline: 116 123
(available 24 hours a day, every day)

Email: jo@samaritans.org

Appendix I – Ethical approval

NEW SCHOOL OF PSYCHOTHERAPY AND COUNSELLING
NSPC Limited
Existential Academy
61–63 Fortune Green Road
London NW6 1DR

Stephanie Yin
[redacted]

5th May 2023

Dear Stephanie

Re: Ethics Approval

As you will be aware, your ethics approval has been granted by Chair's action.

The date of approval was 26th April 2019. This letter acts as evidence of ethical approval should you need it.

Please note that it is a condition of this ethics approval that recruitment, interviewing, or other contact with research participants only takes place when you are enrolled in a research supervision module.

Yours sincerely

Claire Arnold-Baker

Claire Arnold-Baker, Chair of NSPC Ethics Committee

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office@nspc.org.uk www.nspc.org.uk @NSPCinfo

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Appendix J – Full list of themes and sub-themes

The physical dimension

Being towards the body

- Physical changes
- Heightened awareness of the body
- Bodily hatred

The complex and paradoxical expectations and experiences of recovery

- Weight expectations
- Expectations set by healthcare professionals
- Lengthy recovery

Letting go of normality and accepting the givens of illness

- Life beyond CD
- Rules around steroid management

The social dimension

Being dismissed by medical professionals

- Not being heard
- Facing assumptions

Having a large part of the experience ignored

- Frustrating relationships
- Lack of acknowledgement
- Lack of information and support
- Carrying a secret
- Lack of therapeutic impact

- Impact of dependency on steroids

Feeling abused yet safe

- Treatment by others

Negotiating relationships

- Family
- Friendships
- Partners
- Employers

Needing to connect through shared experience

- Drawbacks

Finally being seen and heard

- Sharing my journey

The Psychological dimension

Navigating identity

- Feeling robbed
- Identity and physicality
- Identity and capability

Cushing's as a limit situation

Psychological distress

- Loss and self-awareness

The paradox of being that one in a million

The Spiritual dimension

Vulnerability and choice in the face of mortality

- Threat of adrenal crisis
- Value of life

The quest for meaning

- Why me?
- Purpose

Beliefs

- Agency
- Faith and God

The temporal dimension

The challenge of waiting

- Subjective experience of time

Age

Illness enduring

- Perpetual possibility of recurrence