“They don’t see how tired I am”: An Exploration of the Lived Experiences of Long COVID in Motherhood

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Abstract

Long COVID is a newly emergent chronic illness characterised by complex heterogenous symptoms with varying degrees of impact. Long COVID research is evolving, but there is little research that has focused on exploring how long COVID is experienced in specific life stages, including motherhood, particularly from Aotearoa, New Zealand. Motherhood responsibilities do not disappear despite chronic illness and pose challenges to self and the practicalities of parenting as evidenced in research on other illnesses, like fibromyalgia and chronic fatigue. This thesis explored the lived experiences of a small group of New Zealand mothers living with a medical diagnosis of long COVID. Utilising the methodological approach of interpretative phenomenological analysis, this thesis aimed to detail the complex, shared and idiosyncratic ways mothers experience disruptions to their lifestyles and identities while living with this emergent chronic illness. Five themes were identified: *An Uncertain Illness with "Invisible" Symptoms; Symptoms Impose Lifestyle Restrictions; Mothering Requires an Adapted Approach; Mothers Experience Pressure to "Push Through" Symptoms; and Changing Identity and Self-Reflection*. The debilitating nature of long COVID symptoms imposed functional limitations on the participant's physical, psychological and social lives. In particular, invisible symptoms and the often-contested nature of long COVID became barriers for social participation and mental wellbeing. The participants often internalised good mothering ideologies which contributed to pressures to push through symptoms instead of attending to self-care. In this way, the dynamic interactions of living with long COVID in motherhood posed additional disruptions to maternal wellbeing. By adding to the limited literature on long COVID, this thesis highlights the physical, emotional and social complexities that mothers face living with this newfound chronic illness.

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CHAPTER ONE: Long COVID: An Emerging Chronic Illness

Long COVID is a recently discovered illness that is comprised of long-term multisystemic symptoms following an infection with the COVID-19 virus (Davis et al., 2023). Described as a "worldwide healthcare emergency" (Fernández-de-Las-Peñas et al., 2023, p. 1) and a "mass disabling event" (Smith et al., 2025b, p. 1), long COVID poses a major threat to the health and wellbeing of those affected. Researchers have identified that long COVID is "more than a lingering illness, it is a complex disabling condition that threatens health, livelihoods and dignity" (Elmi & Yusuf, 2026, p. 1). Considering the growing global burden, the Long COVID Consensus Expert Panel have declared urgency for further research into this condition (Ewing et al., 2025).

This chapter will introduce long COVID as an emergent chronic illness with a focus on the nature of long COVID as a medical condition, specifically its diagnosis, symptoms, risk factors and emerging approaches to treatment. I will then introduce the rationale for research on mothers and their experiences of long COVID, followed by the aims and objectives for this thesis.

1.1 The Patient-Derived Origins of Long COVID

Long COVID was first recognised early in the COVID-19 pandemic within online spaces, notably Twitter, whereby thousands of people began to document their experiences living with the prolonged symptoms of Covid-19 (Callard & Perego, 2021). The term 'long hauler' was first used by Amy Watson on X/Twitter referring to her experiences with long-term COVID-19 symptoms using an analogy of long-haul trucking (Lupton & Carey, 2025). A month later, the term 'long COVID' was first used on X/Twitter by academic, Elisa Perego (Lupton & Carey, 2025). During this time medical knowledge and support for prolonged Covid-19 was absent, which meant that social media became a place where people could turn for validation and support. Considering the reliance initial long COVID patients had on finding each other via social media, Callard (2021) claims it was the first illness in history that was established by patients finding

community online. Patient-led activism for the recognition of long-term COVID-19 symptoms was a major contributing factor that ignited the attention of medical professionals, policy and media (Kaplan & Mendenhall, 2024). Now, six years on from the start of the COVID-19 pandemic, scientific understanding seeks to reach a consensus on the heterogenous and complex nature of long COVID.

1.1.1 A Note on Terminology

Since the inception of long COVID, many terms have been utilised to describe this collection of symptoms, these include Long Haul COVID, Post-COVID-19 Condition or Syndrome, Chronic COVID Syndrome, Ongoing Symptomatic COVID-19 and Post-acute Sequelae of COVID (Baig, 2021; Fernández-de-Las-Peñas et al., 2023; Naidu et al., 2024; Phillips & Williams, 2021; Scherer et al., 2022). Currently, all terminology stated above is in use within the literature, which speaks to the emergent state of this disease and variable states of agreement within research communities as the current corpus of literature rapidly expands.

Long COVID experts recommend the term 'long COVID' to describe this condition, as it is the original patient-derived term, it is well understood, simple and accessible to both public and medical professionals alike (Ely et al., 2024). Alternatively used names such as 'Post-acute Sequelae of COVID', have been criticised for their medically arcane jargon which may be an accessibility barrier for non-academics (Ely et al., 2024). Additionally, long COVID researchers have proposed that replacing the patient derived term 'long COVID' with alternatives like 'Post-acute Sequalae of COVID' could cause harm for those suffering by contributing to "medical silencing" whereby patient voices are denied by those in authority (Lupton & Carey, 2025, p. 411; Munblit et al., 2022). Since this thesis is grounded in understanding lived experience, whereby patients are considered the experts of their experiences, it will furthermore use the patient preferred terminology of 'long COVID'.

1.1.2 Establishing a Definition

Within the existing literature, there is a lack of consensus for a formal definition of long COVID (De Las Salas et al., 2025; Gomez-Bravo et al., 2025). Most existing long COVID literature defines the condition using a range of new and persisting symptoms

existing over variable duration with or without a confirmation of past acute COVID-19 infection (Michelen et al., 2021). Gomez-Bravo et al. (2025) analysed the current definitions in use within the literature and found that the most common definitions included those by the World Health Organisation (WHO), the American Centre of Disease Control (CDC) and an array of other definitions including those by the Lancet and the National Institute for Health and Care Excellence (NICE). A significant difference within these definitions is the length of time required until symptoms can be defined as long COVID, these range across the most common definitions from four weeks to six months (Gomez-Bravo et al., 2025).

The variability of definitions and lack of standardisation within current literature poses problems for a unified approach to defining outcomes and treatments across the array of research projects currently underway (De Las Salas et al., 2025). The lack of a standardised definition and an uncoordinated research approach have created unnecessary complications in the recognition of this debilitating condition (Gomez-Bravo et al., 2025). Wisk et al. (2025) found that researchers' use of various definitions for long COVID affected their prevalence estimates. Thus, the array of definitions for long COVID poses problems for the ability to accurately compare the results across studies (Wisk et al., 2025). As the corpus of literature grows along with the recognition of long COVID, its definition will likely also consolidate.

1.2 Long COVID as a Medical Condition

1.2.1 Diagnosis

Long COVID diagnoses require a personal patient centred approach considering the vast heterogeneity of symptom presentations, with currently over 200 reported symptoms (Muleme et al., 2025). The vast array of symptoms linked to long COVID require extended testing to exclude alternative diagnoses (Thomas et al., 2024). However, long COVID can only be diagnosed when people report their symptoms to medical professionals, and poor public understanding of long COVID and the appropriate time to see a doctor creates barriers for people seeking diagnosis and support (Thomas et al., 2024).

Long COVID diagnoses are often met with clinical uncertainty considering the heterogeneity of possible symptoms (O'Hare et al., 2022). Difficulties in understanding the complexities of additional long COVID diagnosis on top of other comorbidities and how they may relate to one another is also a challenge for medical professionals looking to diagnose the condition (O'Hare et al., 2022). Difficulties also arise in the confirmation of prior acute COVID-19 infection due to declines in COVID-19 testing practices (Thomas et al., 2024).

Currently, there are no established biomarkers for the clinical diagnosis of long COVID, however current research has identified potential candidates for future validity (blood-based biomarkers for persistent COVID-19 proteins (Abbasi et al., 2025), biological markers for detecting long COVID brain fog (Fujimoto et al., 2025) and inflammatory biomarkers for neurocognitive symptoms (Mazza et al., 2021)). Without the use of clinical biomarkers for long COVID, clinicians are reliant on patient self-reporting of symptoms, and long COVID self-reports can be met with sceptical attitudes (O'Hare et al., 2022).

A common approach to long COVID diagnosis is a "watchful waiting strategy" (O'Hare et al., 2022, p. 7). This strategy often includes submitting patients to multiple rounds of testing, specialist referrals, and lengthy periods of symptom monitoring. Consequently, people with long COVID can experience significant delays for diagnostic confirmation while continuing to live with debilitating symptoms (Thomas et al., 2024). In an analysis of long COVID diagnosis in the UK, women waited significantly longer than men for a long COVID diagnosis (Prociuk et al., 2025), potentially highlighting gender disparities. It has been previously established that women often receive later diagnoses in a range of health conditions compared to men (Westergaard et al., 2019).

1.2.2 Symptoms

Long COVID manifests as a multiorgan illness characterised by prolonged debilitating symptoms that can affect nearly every organ system (Davis et al., 2021), including respiratory (Nguyen Hai, 2024), reproductive (Maham & Yoon, 2024), dermatological (Cayón Figueroa et al., 2024), neurological (Boutet et al., 2025), and cardiovascular (Barbosa et al., 2025). In their systematic review, Michelen et al. (2021)

discovered over 60 heterogenous symptoms of which weakness, malaise, fatigue, impaired concentration and breathlessness were the most common. The widespread heterogenous array of symptoms present in long COVID has made it a difficult condition to diagnose and understand.

In their study of 3,762 people with long COVID, Davis et al. (2021) found that 85% of people experienced symptom relapses after exercise, stress, physical and mental activities. This is consistent with other research that characterises long COVID by the experience of post-exertional malaise (PEM) (Appelman et al., 2024). PEM is the increased intensity of symptoms following both physical and cognitive exertion, although often more quickly after physical exertion (Hartle et al., 2021). For people experiencing PEM, physical and cognitive exertion can be caused by daily activities such as preparing food, cleaning the home or driving the car (Hartle et al., 2021). Research identifies PEM as a fundamental feature of long COVID (Garbsch et al., 2025).

1.2.3 Risk factors

A range of factors have been identified for people at risk of getting long COVID. Sudre et al. (2021) conducted The COVID Symptom Study which informed a predictive model regarding the characteristics of an individual likely to transition from acute COVID-19 to long COVID. Demographic characteristics associated with long COVID were severity of symptoms, female sex, older than 50 years, those with comorbidities, and a higher body mass index (Fischer et al., 2025; Sudre et al., 2021). Repeat COVID-19 infections and people hospitalised for acute COVID-19 also have an increased risk of long COVID (Tsampasian et al., 2023). Social determinants of health have been evidenced as risk factors for long COVID, including people who live with disabilities (Hall et al., 2024) and those with high levels of social disadvantage (Xiang et al., 2025). These findings highlight that access and healthcare inequalities may be contributing factors to the burden of long COVID (Xiang et al., 2025).

The focus of this research is on mothers, and all my participants were of female sex, therefore it was important to consider the context of gender in long COVID experiences. It has been commonly shown throughout the long COVID literature that the female sex has a higher risk of having long COVID than the male sex and is thus

overrepresented in long COVID statistics (Agarwal et al., 2024; Fernández-de-Las-Peñas et al., 2022; Fernández-de-Las-Peñas et al., 2023; Hanson et al., 2022; Stewart et al., 2021; Toepffer et al., 2025; Tsampasian et al., 2023; Wang et al., 2025). It is important to note that many factors may contribute to this phenomenon, including that females are more likely to seek healthcare compared to males (Thompson et al., 2016), along with biological mechanisms in female bodies. Multiple biological mechanisms seem to pose greater risk for females, such as the viral attack on female sex hormones, differences in female immune system responses and differential expressions of particular enzymes associated with the effects of COVID-19 in cells (Farré et al., 2025; Fonte, 2025). Within the female cohort, middle aged/older females are more likely to get long COVID, but to date there is uncertainty as to why with some medical professionals suggesting it is to do with the immune system's response (Prociuk et al., 2025).

1.2.4 Prevalence

It is difficult to accurately estimate the global prevalence of long COVID, and variability exists in estimated prevalences due to study design, measurement approaches and definitions (Baker et al., 2023). The largest study to date, a mega-systematic review, pooled the global prevalence of long COVID across 144 different studies and found that 36% of adults who survive the initial COVID-19 infection went on to experience long COVID (Hou et al., 2025). However, for other studies variability in designs, definitions and measurements indicate a variable prevalence around 7-45% (Halas et al., 2025; Heath et al., 2025; O'Mahoney et al., 2023; Shi et al., 2025; Zaazouee et al., 2025). Despite variable prevalence statistics, Woodrow et al. (2023) claim that "given the widespread nature of SARS-CoV-2 infection globally, the burden of chronic illness is likely to be substantial even using the most conservative estimates" (p. 1). Estimates of the economic burden caused by lost labour from long COVID suggest the American economy lost around 12 billion USD in 2022 (Liu-Galvin et al., 2025). Including healthcare costs and productivity losses, in the UK the annual economic burden was estimated to be £8.1 billion for long COVID, which is comparable to that of stroke (£9.4 billion) (Kwon et al., 2025).

1.2.4.1 Long COVID in New Zealand

A recent edition to the New Zealand Health Survey highlights that in the years of 2024 and 2025, 185,000 people (4.3%) were currently living with symptoms of long COVID (Ministry of Health, 2026). However, these individuals are part of a larger cohort of 401,000 people (9.2%) who indicated that they had prior experience of at least one long COVID symptom (Ministry of Health, 2026). This data highlights that around 11.9% of New Zealanders have experienced long COVID symptoms after a known contraction of acute COVID-19 (Ministry of Health, 2026). New Zealand researchers consider the current estimates of long COVID as "highly concerning" considering the long-term impacts on the public health system (Baker et al., 2023, p. 80).

A Public Health Communication Centre briefing from September 2024 estimates the impact of long COVID on the New Zealand economy as an approximate annual productivity loss of $2 billion per year (Kvalsvig et al., 2024b). This figure is a rough estimate, its numbers come from Australian research extrapolated to the New Zealand economic climate (long COVID was associated with a 0.5% loss of the annual Australian GDP) (Costantino et al., 2024). Local studies are needed to quantify the impacts in New Zealand, but authors urge that the significant economic burden necessitates preventative efforts and further research (Kvalsvig et al., 2024b). The New Zealand Long COVID Registry estimate that people with long COVID work between seven and ten fewer hours a week than they did prior to the pandemic (Lorgelly et al., 2024). However, no further detailed analyses of long COVID prevalence or productivity loss have been conducted within New Zealand; the Ministry of Health and Health New Zealand have stated that they have "no plans for long COVID monitoring nor for any economic analysis" (Jackways, 2026, p. 1).

Despite the significant percentage of New Zealanders estimated to be affected by long COVID, the condition is still under-researched and overlooked. This can be evidenced by long COVID's exclusion from phase two of the Royal Commission of Inquiry into New Zealand's response to COVID-19 (Stewart, 2025). However, New

Zealand researchers call for increased government action considering long COVID's "major threat" to health, society, and the economic landscape (Kvalsvig et al., 2024a, p. 3). A qualitative study highlighted a state of disappointment from New Zealanders with long COVID who considered there to be a societal movement towards 'moving on' from COVID-19 despite their continued and uncertain illness prognoses (Rhodes & Douglas, 2025).

1.2.5 Emerging Perspectives on Recovery, Healthcare and Treatment

1.2.5.1 Recovery

The potential for people to either fully or partially recover from long COVID is not well understood and this poses challenges for current healthcare and treatment approaches. Harrison et al. (2024) conducted a synthesis of the existing research on long COVID recovery and found the literature is characterised by uncertainty. Some people with long COVID report gradual improvements towards recovery, however more people discuss recovery as an episodic phenomenon and/or a continual disability (Harrison et al., 2024; O'Brien et al., 2023; Wurz et al., 2022). In their study on long COVID recovery, Lee et al. (2025) found that at an average duration of three years post infection, 39% were experiencing continual improvements to their recovery, 40% were not currently recovering and had plateaued and 20% felt their recovery had worsened. This is similar to another longitudinal study where 30% experienced a decrease, 32% an increase and 37% no change in quality of life after three years with long COVID (Suazo Guevara et al., 2025). Just as long COVID symptoms appear heterogenous so do people's experiences with recovery (or a lack thereof). The episodic nature of long COVID symptoms marks this illness as one of unpredictability and uncertainty, whereby current qualitative research points to a nonlinear recovery trajectory (Harrison et al., 2024).

1.2.5.2 Current Global Healthcare and Treatment Approaches

Research has criticised current practice of long COVID healthcare, describing care as "fragmented" and "poorly coordinated" with various care components often siloed separately (O'Hare et al., 2022, p. 7). In their study on long COVID recovery, Lee et al. (2025) found that 33% were currently receiving healthcare which was striking

considering 84% of participants reported physical and functional limitations. Their participants highlighted a desire for healthcare approaches to be patient-centred through a supportive, validating and understanding care philosophy. Some participants reflected on their experiences with "insufficient [healthcare] support", via difficulty getting doctors' appointments, lack of care continuity through referrals and some highlighting that they had been prematurely discharged (Lee et al., 2025, p. 17). Participants also wished for more mental health support and support for everyday home activities (Lee et al., 2025). Similarly, Hawke et al. (2023) explored patient perspectives on long COVID supports in Canada. Many people with long COVID reported difficulties living with the uncertainty surrounding the nature of long COVID and called for greater understanding of long COVID along with public awareness to improve treatment and healthcare experiences (Hawke et al., 2023).

Within the vast array of unknowns and considering the continually emerging consensus of medical information, current approaches to long COVID treatment are also variable (Raveendran et al., 2021). As pathophysiological mechanisms involved in long COVID remain elusive, no treatment methods exist for long COVID, however treatment for specific symptoms comprises the current approach (Akiyama et al., 2025). Non-pharmaceutical therapies are recommended for people with long COVID with mild symptoms or within the first six months of experiencing symptoms (Zhao et al., 2025). Therapies that show potential to be effective in long COVID include pacing strategies, cognitive behavioural therapy, pulmonary rehabilitation and various pharmaceutical regimes (Elyazed et al., 2024; Kuut et al., 2023; Parker et al., 2023; Rudroff, 2025; Yet et al., 2025; Zhao et al., 2025). Hawke et al. (2022) conducted a systematic review of registered medical trials investigating the success of interventions proposed for treating long COVID. Promising interventions included those for mental health, cognition and wellbeing; however, the authors called for the need to expand the number of research studies committed to developing successful treatment approaches for long COVID (Hawke et al., 2022).

One of the main pieces of advice given to those with long COVID is to pace their physical activity, including lots of rest periods (Parker et al., 2023). Pacing and rest are important considering people with long COVID often experience post-exertional

malaise (PEM) whereby overdoing physical activities can worsen symptoms (Parker et al., 2023). Qualitative research on the experiences people have with long COVID and their ability to pace are complex. Many describe pacing as a living strategy while also having to navigate the adjustments that come with balancing rest and activity (McDuff et al., 2025). Considering the negative effects of overdoing physical activity, researchers call for a cautious approach to exercise with long COVID (Tryfonos et al., 2024).

1.2.5.3 Current rehabilitation advice in New Zealand

New Zealand's Long COVID Rehabilitation Guidelines call for transdisciplinary support grounded in a patient tailored approach with specific recommendations for symptom management (Ministry of Health, 2022). Strategies for managing symptoms include pacing techniques, mental health supports, cognitive rehabilitation and graded exercise therapy (only for people without PEM). A qualitative study of New Zealanders living with long COVID explored patient perspectives on the management of long COVID in primary care (Rhodes & Tutbury, 2025). The authors suggested a series of proposed recommendations from their patient centred research, which included support for navigating the health system; collaboration of long COVID knowledge across health professionals; person-centred approaches; and the creation of a specialised long COVID health clinic (Rhodes & Tutbury, 2025). However, no current supports from the New Zealand government have been discussed in relation to these recommendations, and long COVID symptom management remains in primary care (Rhodes & Tutbury, 2025).

1.2.6 Long COVID and ME/CFS

Long COVID is one of multiple post-acute infection syndromes of which Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Persistent or Posttreatment Lyme Disease Syndrome, and Post Sepsis Syndrome also belong (Dysimmune Research Aotearoa New Zealand, 2024). ME/CFS is a complex and currently poorly understood condition characterised by at least six months of fatigue/exhaustion (Wong & Weitzer, 2021). Early on within the COVID-19 pandemic, members of the ME/CFS community began to speculate about the cross-over with long COVID, specifically Dr Charles Shepherd from the ME Association who acknowledged the similarities (Shepherd,

2020). World Health Organisation classifications of long COVID share similarities with ME/CFS and majority of researchers understand long COVID as an example of a post-viral condition like ME/CFS, except caused by the specific COVID-19 virus (Tate et al., 2023).

Long COVID and ME/CFS share similarly profound impacts on the quality of life and functional abilities of those impacted (Sukocheva et al., 2022; Weigel et al., 2025). Specifically, pain and fatigue pose significant challenges for engaging in daily life for both conditions (Weigel et al., 2025). A similar fundamental characteristic shared by both conditions is PEM induced by physical activities or exercise (Appelman et al., 2024). Vernon et al. (2025) found in their longitudinal observation study that people with long COVID were able to be diagnosed with ME/CFS at least six months after their initial symptoms, they also referred to this as post-COVID-19 Myalgic Encephalomyelitis. Another study found that 51% of long COVID patients meet the criteria for ME/CFS (Dehlia & Guthridge, 2024). Specifically, research has identified that 25 out of 29 known ME/CFS symptoms overlap with symptoms reported by those with long COVID (Wong & Weitzer, 2021).

Researchers have argued that long COVID can be considered a contested illness similarly to ME/CFS (Au et al., 2022; Barker et al., 2022; Sargeant et al., 2025). Contested illnesses are those which face challenges in their diagnosis, illness aetiology and face difficulties for medical acceptance and legitimacy and patients often have their symptoms dismissed (Dumit, 2006). Considering the similarities between long COVID and other infection-related chronic diseases like ME/CFS, Ely et al. (2024) argue that long COVID's emergence within a global pandemic is beneficial for its legitimacy by garnering rapid attention for research on possible treatments. Without global attention to address the global COVID-19 pandemic, long COVID may have suffered a slower and more invisible journey of legitimacy and attention, like ME/CFS (Ely et al., 2024).

1.2.7 Quality of Life

Research has established that long COVID results in substantial reductions in quality of life due to the significant impairments imposed by its symptoms, particularly

for wellbeing and daily functioning (Carlile et al., 2024; Malesevic et al., 2023). Researchers have utilised impactful and emotional language to draw attention to the debilitating and disabling impacts of long COVID. Long COVID has been described as a "silent wave of chronic disability" (Pereira & Morris, 2025, p. 1) as well as a "mass deterioration event" characterised by a "tidal wave of chronic illness" (Mazer, 2022, p. 1). An Australian based study found that people with long COVID reported clinically significant disability and impaired function in daily life (Hitch et al., 2025). The mean results from the World Health Organisation Disability Assessment Schedule 2.0 found a disability level for those with long COVID that was 98% higher than that of the general population (Hitch et al., 2025). All domains of quality of life were impaired by those with long COVID particularly for "vitality, household duties, work/school and societal roles" (Hitch et al., 2025, p. 5). The New Zealand Long COVID registry reported that previously healthy people who developed long COVID consider their health to be poor (51% of Māori and 44% of Pākehā) (Lorgelly et al., 2024). A six-month follow-up further identified that 28% of their participants still considered their health as poor. Strikingly, long COVID health related quality of life scores were similar to that of people living with multiple sclerosis and cancer (Lorgelly et al., 2024).

Working abilities are another area negatively impacted by long COVID. Research has shown that 45% of people reduced their working hours and 22% were not able to work due to their illness (Davis et al., 2021). The experiences of people trying to return to work are full of challenges, including the daily suffering of chronic fatigue and brain fog, challenges around loss of work identities, and invalidation from colleagues and managers from a lack of long COVID understanding (Nielsen & Yarker, 2024).

A particular feature of long COVID as a new emerging condition is the experiences people face with stigma and medical gaslighting (Au et al., 2022). Medical gaslighting occurs when health professionals dismiss, doubt or deny a patient's accounts of their symptoms, including calling patients' own judgements into question (Fuss et al., 2024). Quality of life, particularly mental health, for those with long COVID is also significantly impacted by its social stigma (Scholz et al., 2023), especially for ethnic minority groups (Nyaaba et al., 2025). Long COVID stigma is characterised by the invalidation of its functional impairments and a common experience is the

psychologisation of symptoms (Büchner et al., 2025). Long COVID stigma has been associated with depression and worse physical functioning, while fewer experiences of stigma are associated with improved quality of life (Damant et al., 2025).

1.3 Motherhood: An Important Life Context

Within the group of people currently living with long COVID, a smaller group face the additional challenges of navigating an uncertain chronic illness within the complex and demanding context of motherhood. There is little research based on mothers with long COVID in Aotearoa New Zealand. However, what we do know is that from the New Zealand Long COVID Registry, a high percentage of adults with long COVID (81% of Māori and 77% of non-Māori) reduced or stopped domestic tasks due to the burden of their illness but a low percentage of parents with long COVID (16% of Māori and 10% of non-Māori) reduced or stopped caregiving and childcare duties once getting long COVID (Lorgelly et al., 2024). When considering that parenting responsibilities remain despite illness, this low number reflects that parenting is a role that does not stop at the end of the week. These figures suggest parents may be vulnerable to the additional challenges that come from coping with their illness alongside caregiving responsibilities. This is concerning considering that a high percentage of people with long COVID in New Zealand (88% Māori and 90% of non-Māori) report worsening abilities to complete their usual daily activities (Lorgelly et al., 2024). Considering the often gendered nature of parenting in western societies (Horne et al., 2018; Kamp Dush et al., 2018; Pedersen, 2012), mothers in particular may experience parenting disruption through chronic illness.

Currently, there are few studies that explore the impacts and intersections of living with long COVID in the life context of motherhood. However, the studies that do exist (e.g. León-Herrera et al., 2025; Riley et al., 2025; Schröder et al., 2024; Silletti et al., 2025; Smith et al., 2025b), highlight the compounding debilitating experiences of managing motherhood with chronic long COVID symptoms. Specifically, these studies show that mothers experienced impairments in their ability to carry out family and domestic tasks, along with limited abilities for social life participation (Schröder et al., 2024). Impaired abilities for conducting caregiving and household tasks were

particularly associated with the burden of brain fog and fatigue which consequently sparked feelings of mothering guilt (Silletti et al., 2025). Additionally, long COVID was associated with maternal depression and anxiety (Silletti et al., 2025). The authors highlighted that the additional challenges of caring for young children while also living with long COVID may both compound the psychological impacts and contribute to worsening mental health (Silletti et al., 2025).

Research has identified gaps for the nuanced experiences people have within long COVID (Baz et al., 2021), along with the need to understand lived experiences to adapt to the presence of long COVID within our communities (Stokoe et al., 2022). To do this, long COVID guidelines need to be grounded within lived experience research (Gorna et al., 2021). Considering the call for urgent research on people juggling family care responsibilities and illness (Smith et al., 2025b), a detailed understanding of how mothers experience long COVID remains elusive.

1.4 Research Aims and Objectives

This thesis seeks to explore the lived experiences of a group of New Zealand mothers living with the medical diagnosis of long COVID. Considering the onset of the COVID-19 pandemic six years ago, qualitative research exploring the lived experiences of people living with the long-term symptoms of this illness are still limited. Additionally, few studies have considered the potential intersections that may arise from the challenging and demanding life context of motherhood. By exploring the ways mothers have lived with and made sense of their long COVID illness, this research aims to provide space for their stories and experiences to be heard.

This research will employ interpretative phenomenological analysis to detail the complex, shared and idiosyncratic ways mothers make sense and experience changes to their physical, emotional and social lives during their long COVID illness.

The research objectives are to:

- Explore how mothers experience and understand the ways long COVID has impacted their lifestyles.

- Develop an understanding of how participants experience and make sense of changes to their sense of self.
- Explore how participants experience the nuanced intersections of living with long COVID within the life context of motherhood.
- Provide insights for health professionals who seek to support mothers living with long COVID.

CHAPTER TWO: An Overview of Relevant Literature

This chapter is comprised of three sections. Section One draws upon recent literature to discuss the various impacts that long COVID has on an individual's quality of life. Using the organising structure of the dynamic biopsychosocial model (Lehman et al., 2017), this first section includes the physical, psychological, social and contextual elements of the long COVID experience. Section Two introduces the life context of motherhood within the gendered nature of caregiving and neoliberal mothering norms. This section aims to provide important context for section three. Section Three discusses the existing literature on the experiential intersections of long COVID and motherhood, including discussion of mothering during the COVID-19 pandemic. Overall, this chapter provides an array of background literature that forms the foundation of this thesis project.

2.1 Section One: Long COVID and Quality-of-Life Impacts

The biopsychosocial model of illness, first developed by Engel (1977), provides a conceptual and holistic understanding of the biological, psychological and social factors that contribute to health and illness. This approach is useful when considering people as not only a product of their biology, but also the influence of their psychosocial contexts (Roberts, 2023). The biopsychosocial model has been adapted over time to include additional elements such as the digital world (Scherer, 2020), the environment (Stineman & Streim, 2010), sociotechnical systems (Card, 2023), and an emphasis on social groups (Haslam et al., 2019). Another adaptation, titled the *Dynamic Biopsychosocial Model* offers a systems understanding of illness that is not just as the presence of biopsychosocial elements, but also their interactions with one another in various contexts (Lehman et al., 2017).

The following sections outline existing literature on the quality-of-life impacts of long COVID. These have been organised with attention to the dynamic biopsychosocial model, that is the biological, psychological, social, and contextual elements of long COVID.

2.1.1 Impaired Physical Functioning

It is well established that people who live with long COVID experience the debilitative consequences of impaired physical abilities (Chasco et al., 2022; Humphreys et al., 2021; Ladds et al., 2020; Pearson et al., 2022; Wiertz et al., 2025; Wurz et al., 2022). Long COVID symptoms (e.g. fatigue, pain, breathlessness) impair usual functional abilities and these transform normal routines into challenging daily struggles (Leggat et al., 2024). Specifically, fatigue, one of the main symptoms, becomes a significant barrier for taking part in everyday activities (Kennelly et al., 2023). A challenging nature of long COVID fatigue is that both physical and cognitive effort can exacerbate its intensity (Kennelly et al., 2023). For many people the consequences of fatigue mean living housebound and/or bedbound for many months or more (Humphreys et al., 2021; Ryan et al., 2025; Sirotiak et al., 2026). A systematic review of long COVID literature highlights the challenges of living with its physical impacts, specifically difficulties in completing daily activities, including leisure and hobbies (Hossain et al., 2023). Depending on the intensity of symptoms, some have difficulty or are unable to complete household chores and/or personal care needs due to the additional fatigue these activities create (Burton et al., 2022; Spence et al., 2023).

Lifestyle changes often impede regular routines and daily activities, which some people respond by scheduling in periods of rest (Ryan et al., 2025). Need for rest is particularly emphasised in those who experience the physical and mental burn out from post-exertional malaise (PEM) (Kennelly et al., 2023). People who experience PEM see an increase in symptom intensity after physical and cognitive effort, although physical activity triggers PEM quicker (Hartle et al., 2021). For example, people with long COVID have identified the burdensome impact of symptoms that hinder self-care activities, cooking, cleaning, exercising, gardening, driving and reading (Chasco et al., 2022; Pearson et al., 2022). Fatigue is the main symptom that contributes to significant challenges in housekeeping and if people manage to complete these chores, they often suffer the consequences of exhaustion (Chasco et al., 2022). This means that many people have felt the need to prioritise their energy for essential tasks, such as laundry and cooking, over leisure hobbies that formerly gave life value and excitement (Leighton et al., 2025).

The negative quality of life impacts imposed by reduced physical abilities are compounded by the cognitive and emotional impacts (Humphreys et al., 2021). Brain fog is a commonly debilitating impact of long COVID which is characterised by difficulties in focus, memory, attention and increased frustration (Kennelly et al., 2023). Some people with long COVID are forced to restrict usual activities for risks to their safety imposed by mental overload and brain fog, such as cooking and driving (Kennelly et al., 2023). Some people have highlighted that the consistent impairments of fatigue and brain fog have left them with an overwhelming sense of having lost their freedom and autonomy (Humphreys et al., 2021; Moretti et al., 2022).

Researchers highlight long COVID as "a confusing illness of relapsing and remitting symptoms" which contribute to the unpredictable limitations for daily functioning (Ladds et al., 2020, p. 9). The unpredictable nature of symptom presentation and intensity is often a confusing experience for those suffering (Wurz et al., 2022). Many people have found it challenging to plan daily activities within the bounds of symptoms constantly in flux (Chasco et al., 2022; Leggat et al., 2024; Pearson et al., 2022; Sirotiak et al., 2026). Researchers have described the confusion and uncertainty that comes with long COVID as an 'episodic disability' (O'Brien et al., 2023; O'Brien et al., 2025).

Research exploring how people manage their symptoms is limited. However, some qualitative research has highlighted various strategies for the navigation of everyday living (Leggat et al., 2024). These include seeking medical advice, self-monitoring symptoms, trial and error of 'safe' ideas (e.g. medications, rest schedules, nutraceuticals), prioritising self-care and social supports (Leggat et al., 2024).

2.1.2 Mental Health Consequences

Anxiety and depression are significantly associated with long COVID (Engelmann et al., 2024), and people continue to report poor mental health with research finding this may last up to 15 months after initial assessment (Gaughan et al., 2024). In their study on emotional health, Ribeiro-Carvalho et al. (2025) found that over half of their participants had symptoms that suggested disorders of depression, anxiety and stress. Researchers have described people with long COVID as experiencing a

"deep emotional impact" (Ryan et al., 2025, p. 11). For some people, the daily stress of their symptoms triggers feelings of poor self-esteem and guilt about not being able to fulfil the daily responsibilities of their lives, including paid work, housework and self-care (Callan et al., 2022; Humphreys et al., 2021). People report having to "mourn the life they have lost" (Samper-Pardo et al., 2023, p. 5). Emotional distress is particularly prominent considering social isolation and loneliness are also common experiential elements of long COVID (Hossain et al., 2023).

Emotional wellbeing in long COVID has been linked to people's perceptions of their ability to control and manage their symptoms (Leggat et al., 2024). For some people, this loss of autonomy is followed by grief and frustration over the loss of formerly active and independent selves (Burton et al., 2022; Sirotiak et al., 2026). Daily psychological ambiguity is described as a "rollercoaster" (Leggat et al., 2024, p. 8), and for some, ambiguity and symptom relapses are an extremely frustrating component of the illness (Burton et al., 2022). This fluctuating nature of symptoms can become a barrier for hopeful recovery (Lieberwerth & Niemeijer, 2024). A systematic review of long COVID highlights experiences of emotional distress, guilt, hopelessness and fatalism over their uncertain illness projection (Hossain et al., 2023). Poorer mental health has been associated with the unpredictability of living with a new and uncertain illness, of which constant fears for the future take an emotional toll (Burton et al., 2022; Kennelly et al., 2023; Skilbeck et al., 2023). People with this illness particularly fear the risk of reinfection with COVID-19 and the unknown potential for an exacerbation of their existing symptoms (Leighton et al., 2025; Samper-Pardo et al., 2023). Over time, fears around uncertainty lead to a sense of hopelessness and depression, which include suicidal thoughts (Kennelly et al., 2023; Samper-Pardo et al., 2023). Living with continual uncertainty and the unknown prospect for recovery can leave people facing significant distress and grief (Sirotiak et al., 2026).

Other than anxiety and depression, research has identified additional psychological impacts of long COVID which include post-traumatic stress disorder, sleep disorders and cognitive dysfunction, which all negatively impact daily functioning and wellbeing (Shen et al., 2025). Frequent shifting moods also feature as a

consequence of the illness which can manifest in emotional and sensory overwhelm (Kennelly et al., 2023).

2.1.2.1 A changing sense of self

An altered sense of self as a result of becoming sick with long COVID is a well reported phenomenon within the literature (Burton et al., 2022; Callan et al., 2022; Hossain et al., 2023; Humphreys et al., 2021; Kennelly et al., 2023; Leggat et al., 2024; Moretti et al., 2022; Pearson et al., 2022; Skilbeck et al., 2023) and for many people, life is divided between pre- and post-long COVID. Changes to identity mean that people often feel like a different person since becoming ill (Ryan et al., 2025). The barriers to taking part in usual activities that gave life meaning and purpose contribute to loss of former selves (Leggat et al., 2024; Leighton et al., 2025). For some, loss of former identity was linked with a reduced sense of self-worth, particularly if former identities were considered valuable (Callan et al., 2022; Holmes et al., 2025). For example, former identities as active people are challenged by the sudden loss of physical capabilities, which leaves people dealing with the loss of formerly valued hobbies (Spence et al., 2023). A sense of self as capable and productive workers is also challenged by illness, particularly for people self-identifying as career-orientated (Nielsen & Yarker, 2024; Spence et al., 2023). Research by Spence et al. (2023) highlight a three-part process of biographical identity change in long COVID, whereby people move through phases of acknowledging, navigating and reconciling changes to former identities.

The loss of former identities, for some, reflect a deeper existential loss of knowing their new place in the world (Fang et al., 2024; Leighton et al., 2025). Existential reflections prompted revaluations of life purpose, meaning and the reconstruction of new identities as a person living with the functional limitations of an uncertain illness (Fang et al., 2024; Lieberwerth & Niemeijer, 2024). Questions around the meaning of life and illness force people to find new purpose and shift values, often from work and productivity towards family and self-care (Lieberwerth & Niemeijer, 2024). This identity loss, for many people, is a deeply painful and emotional experience (Fang et al., 2024). Across these studies, the acknowledgement and acceptance of the loss of former identities, takes an emotional toll on people. Accepting an altered sense of self can be mental battle, particularly to come to terms with their reduced physical functioning

compared to pre-long COVID (Humphreys et al., 2021). This change in identity often comes along with grieving over former selves, including identities associated with work and productivity, socialising and hobbies (Kennelly et al., 2023). Considering the unknown permanency of symptoms, people with long COVID faced the continued speculation, questioning if changes to their self-identities were permanent too (Pearson et al., 2022).

While most research highlights the poor mental health consequences of living with long COVID, there is less focus on how mental health can be enhanced. However, research does point to reduced anxiety symptoms for people with larger social circles, and that living with other people has been associated with less depression compared to living alone (Gerhards et al., 2026). Another protective factor is the importance of talking therapies. Specifically, those who have sought mental health supports report that talking through their sadness, anxiety, anger and grief has helped them to adjust to being ill (Samper-Pardo et al., 2023). Researchers highlight the importance of acknowledging the mental adjustments people with long COVID face, considering the widespread life changes imposed by their sickness (Pearson et al., 2022). Adjustments can be adaptive (e.g. acceptance) or maladaptive (e.g. denial, social isolation) as people begin to learn the new boundaries and capabilities of living in a sick body (Pearson et al., 2022).

2.1.3 Interpersonal Impacts

2.1.3.1 Social Relationships

Social support is significantly beneficial for the wellbeing of people living with long COVID (Burton et al., 2022; Kennelly et al., 2023; Ryan et al., 2025; Samper-Pardo et al., 2023; Sirotiak et al., 2026). Many people rely on practical support from friends and family to 'fill in' for their functional limitations (Leighton et al., 2025). For example, both practical supports, such as taking loved ones to medical appointments, cooking, shopping (Burton et al., 2022) and emotional support have been emphasised as valuable aspects of social relationships (Ryan et al., 2025). Considering the heterogenous array of symptoms and their intensities, some people are more reliant on

family and friends for support, including help with personal care needs in the home (Sirotiak et al., 2026).

Despite the positive impact of social relationships, many people with long COVID experience reduced tolerance for socialising due to physical and mental fatigue (Kennelly et al., 2023; Wiertz et al., 2025; Wurz et al., 2022). They often report feeling socially isolated, often from a lack of family, friend and medical support (Chasco et al., 2022; Moretti et al., 2022; Sirotiak et al., 2026) and loss of hobbies and leisure activities (Leighton et al., 2025). The nature of fluctuating symptoms impeded abilities for people to interact with social activities and peer support groups that would otherwise enhance wellbeing (Sarma et al., 2025). Fatigue is a significant barrier for people feeling able to take part in social and leisure activities, which means people avoid social interactions for the sake of preserving what little energy they have (Burton et al., 2022). For example, difficulty managing conversations and remembering names leaves some people embarrassed, and this can become a barrier to participating in social events (e.g. family Christmas gatherings) (Leighton et al., 2025).

Feelings of isolation are often associated with social interactions whereby the legitimacy of the illness is dismissed and/or people fail to understand its debilitating impacts (Kennelly et al., 2023; Moretti et al., 2022; Pearson et al., 2022; Wiertz et al., 2025). Some people lose friendships over conflicts surrounding vaccination status and the legitimacy of the COVID-19 pandemic in general (Aghaei et al., 2022). Reduced abilities to maintain social contacts outside of the home also contributed to a sense of not belonging (Pearson et al., 2022). For some people, it was the invisibility of their symptoms (i.e. fatigue, brain fog, pain) that became a barrier for feeling connected socially (Leggat et al., 2024; Pearson et al., 2022). Negative social interactions with friends and family lead some people to question if they continue potentially superficial relationships (Sirotiak et al., 2026, p. 6). Leggat et al. (2024) highlights how long COVID reveals the “true colours of personal communities” in the sense that some relationships are strengthened and others weakened, as people experienced both supportive and dismissive attitudes from friends and family (p. 1).

People with long COVID have highlighted how socio-cultural norms that discourage discussions around illness and disability create a pressured environment for

people to ignore their illness symptoms (Smith et al., 2025a). This often leads to a worsening sense of wellbeing and a sense of "individualised failure" and self-blame (Smith et al., 2025a, p. 4). Concerningly, for some people the pressure to ignore their illness discourages them from seeking healthcare (Smith et al., 2025a). This lack of social understanding and support for long COVID has left many people feeling socially isolated (Smith et al., 2025a).

Qualitative research by Sirotiak et al. (2026) highlights recommendations made by people living with long COVID for improved social supports. These included improving public education, sympathy, respect and acknowledgement for its debilitating impacts so that people may be more willing to offer support (Sirotiak et al., 2026).

2.1.3.2 Employment and Finances

Qualitative research often highlights that people with long COVID fear for their job security (Aghaei et al., 2022; Chasco et al., 2022; Moretti et al., 2022), particularly when some people are unable to return to work due to significant fatigue and brain fog (Burton et al., 2022). In their survey of employment status Jaber et al. (2025) found that 15% of their participants experienced reduced employment and this was often for those experiencing moderate/severe impacts on their physical and mental health. Recent research from the US found that people with the most severe activity limitations faced the greatest financial hardship (27% more than those without COVID-19) and particularly, those with mild activity limitations also faced significantly greater financial hardship than people without COVID-19 (Das, 2026). These experiences of financial and employment uncertainty contribute to both emotional and financial distress (Aghaei et al., 2022; Gaughan et al., 2024; Hossain et al., 2023; Ryan et al., 2025; Stelson et al., 2023). Specifically, many participants lost their jobs, worked less and/or faced increased medical expenses (Callan et al., 2022; Chasco et al., 2022; Smith et al., 2025a; Wiertz et al., 2025; Wurz et al., 2022). Some people were even forced into taking early retirement due to the impact from symptoms (Gaughan et al., 2024). A combination of these factors all contributes to an overwhelming sense of financial stress for these people living with ongoing long COVID (Gaughan et al., 2024).

Research highlights that people facing difficulties working because of long COVID experience both external and internalised criticism. External criticism can come from employers, whereby some have expressed frustration with people returning to work who were not able to return to their previous level of function prior to long COVID, and for some this came with pressures to resign (Sirotiak et al., 2026). People report facing negative interactions with colleagues critical over their use of sick leave and accusing them of faking symptoms (Clutterbuck et al., 2024). Chasco et al. (2022) discuss how brain fog not only affected employers' perceptions of work capabilities, but also how people with long COVID perceive themselves. Research highlights that some people consider the inability to continue working as a personal sense of failure (Smith et al., 2025a) and shame for facing difficulties with previously mundane tasks (Chasco et al., 2022).

Many people with long COVID report the desire to return to work for the financial and socialisation benefits that come with work routines (Stelson et al., 2023). However, the episodic nature of symptoms and changing intensities was a barrier to be able to successfully return to work, which only added to fears around an uncertain future (Nielsen & Yarker, 2024; Stelson et al., 2023). Research has highlighted key features for a successful return-to-work experience. Supportive healthcare providers were a necessary component for access to sick leave, compensation and other workplace accommodations, whether or not people had this was an important feature for successful return to work (Stelson et al., 2023). Interestingly, people who were offered flexible work arrangements (i.e. working from home and flexible hours) were able to keep working, for these people continuing to work was a positive and much valued experience (Nielsen & Yarker, 2024; Sirotiak et al., 2026; Smith et al., 2025a). Additionally, workplaces that validated workers long COVID identities and struggles were seen as valuable (Nielsen & Yarker, 2024).

2.1.3.3 Stigma and Gaslighting

Researchers have recognised long COVID as perhaps the "largest and most significant contested illness surge in modern history" (Ballard, 2021, p. 5). The contestation surrounding the legitimacy of long COVID has created a social climate where people face conflict and stigma (Sargeant et al., 2025). Stigma within health

conditions can be defined as the “social disqualification” of a group of people according to their state of illness (Weiss et al., 2006, p. 277). Understanding health-related stigma is important as it can further reduce quality of life and wellbeing for those experiencing it (Weiss et al., 2006).

Unfortunately, experiences of social stigma are a common feature of research on long COVID (Aghaei et al., 2022; Kennelly et al., 2023; Moretti et al., 2022; Ryan et al., 2025; Sirotiak et al., 2026). Researchers have identified various forms of stigma which include enacted (experiences of discrimination), internalised (negative self-concept), and anticipated stigma (predicting future experiences of bias and discrimination) (Pantelic et al., 2022b). In their survey, Pantelic et al. (2022b) found that 95% of people experienced stigma ‘sometimes’ and 76% experienced it ‘often/always’, with anticipated and internalised stigma being more common than enacted stigma. It is important to note that even though a large majority of people experience some form of stigma, not all people do (Burton et al., 2022; Samper-Pardo et al., 2023).

Qualitative research has highlighted that long COVID stigma experiences are diverse, but common experiential elements include the trivialisation of the impact of symptoms and being blamed for the cause of their own illness (Kennelly et al., 2023). Some people report facing internalised stigma and embarrassment over being sick, and their “vague symptoms” that could be dismissed by other people (Clutterbuck et al., 2024, p. 9). Sigma also exists in workplace environments, whereby colleagues and employers fail to understand the functional impacts of their symptoms (Chasco et al., 2022; Nielsen & Yarker, 2024; Stelson et al., 2023). People report that it took extreme circumstances such as medical emergencies (e.g. fainting at work) for other people to eventually take their illness seriously (Ryan et al., 2025). A consequence of experiencing social stigma is that some people stop talking about their illness in social settings, and/or avoid socialisation which only adds to existing feelings of isolation and abandonment (Aghaei et al., 2022; Kennelly et al., 2023; Moretti et al., 2022).

Medical gaslighting is another well-established phenomenon within long COVID experiences (Ladds et al., 2020; Lieberwerth & Niemeijer, 2024; Moretti et al., 2022; Skilbeck et al., 2023; Smith et al., 2025a; Wurz et al., 2022). Medical gaslighting occurs when people’s personal accounts are dismissed or invalidated by medical

professionals in ways that lead them to re-question the nature of their own reality (Fuss et al., 2024). Medical gaslighting can be understood within power dynamics of the medical encounter, whereby medical professionals hold the power to claim what is real, what needs to be followed up, and what does not (Sebring, 2021). In this way, patients are subjected to the decisions of their healthcare providers (Sebring, 2021). Along with this power dynamic, particularly for conditions that are difficult to diagnose and with a lack objective measures, medical gaslighting is common (Witvliet, 2022). People with long COVID often report experiences of their medical professionals not believing their symptoms, lack of acknowledgement or empathy and ignorance of available support options and/or referral (Ladds et al., 2020). Frustrating interactions with medical professionals are associated with "a heavy sense of loss and stigma" (Ladds et al., 2020, p. 9), and feelings of abandonment (Mullard et al., 2024).

A common example of medical gaslighting is the psychologisation of symptoms, whereby symptoms are attributed to mental health, such as patients being 'just anxious' (Au et al., 2022; Burton et al., 2022; Callan et al., 2022; Moretti et al., 2022; Ryan et al., 2025; Sirotiak et al., 2026). This leads people to self-doubt and question the true nature of their symptoms (Sirotiak et al., 2026). Dismissal of symptoms is a particularly prominent experience for women, who are likely to have their long COVID symptoms attributed to mental health concerns (Clutterbuck et al., 2024). Female respondents tend to report more negative interactions with medical professionals, including the attribution of their symptoms to "women's troubles" (Au et al., 2022, p. 6), menopause and aging (Clutterbuck et al., 2024; Leggat et al., 2024). Long COVID is not the only chronic health condition that women experience medical gaslighting, unfortunately it is a common experience across many pain conditions (Hintz, 2023). Fears of seeking long COVID healthcare and potential gaslighting and/or racial discrimination exists particularly for people belonging to ethnic minorities which adds complications to receiving supportive healthcare (Mullard et al., 2024). Worryingly, research has identified that experiences of long COVID stigma have led to the avoidance of seeking healthcare for the fear of judgement and further criticism from medical professionals (Clutterbuck et al., 2024; Van de Vyver et al., 2021).

2.2 Section Two: Motherhood and Social Expectations

2.2.1 The Gendered Nature of Parenting and Household Labour

In the transition into parenthood, traditional gendered narratives of what motherhood looks like are associated with gendered inequalities which transfer most of the caregiving burden to mothers (Sevón, 2012; Williamson et al., 2023). Social expectations for mothers and fathers often prescribe their roles and responsibilities, notably that mothers are primary caregivers (Araújo Martins et al., 2014; Pedersen, 2012) and homemakers (Horne et al., 2018). For example, Kamp Dush et al. (2018) found that when mothers cared for children, 47% of the time fathers engaged in leisure activities. However, when fathers engaged in childcare, only 16% of the time mothers engaged in leisure and this phenomenon existed despite both mothers and fathers engaging in paid work (Kamp Dush et al., 2018).

The gendered nature of parenting and the socialisation of women to the maternal role of homemaker, contributes to an often-gendered experience of household labour (Coltrane & Shih, 2010). In their study, Horne et al. (2018) found that of across the life stages of the transition to adulthood, young adulthood and midlife (i.e. 25-43 years old), women did more housework than men. Other research has specified that when mothers perform household chores, 35% of the time fathers tend to engage in leisure activities. However, inequalities were revealed when their findings indicated that mothers engaged in leisure only 19% of the time fathers did housework (Kamp Dush et al., 2018). The often-gendered nature of parenting is consistent with social role theory which explains gender differences in terms of gender stereotypes that prescribe socially constructed social roles (i.e. mothers should be nurturing) (Reich-Stiebert et al., 2023).

The gendered division of childcare and housework contributes to the phenomenon of the 'maternal mental load' (Dean et al., 2022) and research identifies that mothers perform more mental labour of parenting and housework than fathers (Reich-Stiebert et al., 2023). It is the combination of both the cognitive and emotional work of caring for families that leads to a sense of maternal mental burn out (Dean et al., 2022). The invisibility of this work, its tendency to creep into other facets of life (work, leisure, sleep etc.) and its consistent presence is what contributes to its

overwhelming nature (Dean et al., 2022). Researchers indicate that the negative impacts of constant mental load on the brain lead to “undeniable” impacts on maternal health and wellbeing (Callaghan et al., 2024, p. 764). Women and mothers tend to experience more harmful impacts from this increased cognitive and emotional labour, such as heightened stress and reduced sense of wellbeing in life and relationships (Reich-Stiebert et al., 2023). The mental load of mothering can be exacerbated by social factors like socio-economic stressors, single parenting and the social expectations for good mothers (Callaghan et al., 2024). Specifically in the realm of motherhood, extensive literature has been devoted to the understanding of what constitutes good mothering and the impact this has on maternal mental wellbeing.

2.2.2 Societal Expectations for Good Mothers

Sometimes described as the “motherhood myth” social norms and expectations in western societies surround an idealised form of motherhood (Constantinou et al., 2021, p. 866). These expectations for ‘intensive mothering’ claim that good mothers place their childrearing role above everything else (Hays, 1996), emphasising the maternal value of self-sacrifice (Williamson et al., 2023). Mothers’ understandings of what constitutes good parenting include having a reliable, structured and always accessible presence in their children’s lives (Pedersen, 2012; Schmidt et al., 2025). Pressures for mothers to be constantly available reach beyond just their physical presence, but for the complete attention and devotion to children’s needs (Rúdólfsdóttir & Auðardóttir, 2024). Expectations for mothers to have complete maternal devotion to their children aligns with other research suggesting that attention to children is a primary feature of good mothering (Budds et al., 2017; Schmidt et al., 2025). Not only are mothers expected to be fully attentive to their children but also feel joyous and happy by their child centredness (Schmidt et al., 2025). For example, research by Kerrick and Henry (2017) identifies a “master narrative” that mothers should have “overwhelming, positive and immediate feelings” of connection to their children and babies (p. 1). Additionally, even though motherhood is expected to be exhausting, good mothering ideologies claim that mothers must prioritise their mother role above all others (Schmidt et al., 2025). Mothers in neoliberal societies face expectations of perfectionism regarding this social role, and these expectations influence how they see

themselves (Henderson et al., 2016). Researchers claim that these social expectations conflict with maternal lived experience, thus providing space for tensions between idealised vs lived motherhood (Kerrick & Henry, 2017).

Schmidt et al. (2023) conducted a comprehensive scoping review of the literature published in the last two decades on the social norms of motherhood in WEIRD (Western, Educated, Industrialised, Rich, and Democratic) countries. This study was the first of its kind to provide an explicit overview of mothering norms in this context. They established five prevailing social norms which were: the present mother (fully attentive and self-sacrificial); the future-oriented mother (attentive to children's successful development); the working mother (contribute to the labour market, but not at the expense of mothering); the public mother (informed and self-aware in both private and public settings); the happy mother (positive feelings towards their role as mother) (Schmidt et al., 2023).

It is important to note that the good mothering ideologies discussed above are predominantly circulated amongst white, western, middle-class mothers in heterosexual relationships. Some researchers argue that notions of good mothering exist across "race, ethnicity, social class and sexuality" however the ways this manifest will likely vary accordingly (Sutherland, 2010, p. 312). For example, research on the presence of good mothering norms in the context of queer parents suggest some assimilate to the prevailing standards and some explicitly and/or implicitly challenge such norms (Park, 2019).

2.2.3 Consequences of Mothering Norms

Research on the effects of intensive mothering norms, specifically the pressure to be 'perfect' mothers, has been associated with a number of negative outcomes including parental burn out and poor emotional wellbeing (Meeussen & Van Laar, 2018; Milman & Sternadori, 2024). Maternal pressure to be perfect can increase stress and the preoccupation of avoiding mothering mistakes (Meeussen & Van Laar, 2018). Considering emotional wellbeing, numerous studies have found that good mother ideologies also place mothers at risk for maternal depression (Saint Denny et al., 2025; Sonnenburg & Miller, 2021). It seems that failure to meet these ideological standards

leads to internalised guilt which may be what predisposes mothers to depression (Sonnenburg & Miller, 2021). The negative mental health consequences of good mothering norms may also impact on mothers who do not believe in them (Henderson et al., 2016). Research has found that the internalised guilt from not upholding good mothering standards has negative mental health consequences for mothers who consciously follow these standards and those who do not (Henderson et al., 2016). In this way, all mothers in western societies are at risk for feeling inadequate from such pervasive standards (Henderson et al., 2016).

Mother Guilt

If mothers perceive they have deviated from these social norms, emotional responses are resoundingly negative and one of the most prominent emotional responses is guilt (Constantinou et al., 2021). With the pervasiveness of good mothering ideologies in neoliberal countries, maternal guilt and shame have become closely intertwined with the experience of mothering as a whole (Sutherland, 2010; Williamson et al., 2023). Narratives of guilt and shame have been found to be more common among the lives of mothers compared to fathers, which likely reflects the maternal norms of perfectionism and the dominance of mothers as primary caregivers (Rúdólfsdóttir & Auðardóttir, 2024). Researchers have argued that good mothering ideologies place mothers in danger of experiencing increased levels of guilt and shame surrounding discrepancies between their actual and idealised performance of motherhood (Liss et al., 2013; Sutherland, 2010). Mothering guilt can be experienced when other social roles (e.g. paid work) take mothers away from childcare responsibilities (Pedersen, 2012; Rúdólfsdóttir & Auðardóttir, 2024). Specifically, it has been shown that the more hours per week mothers worked, the greater maternal guilt they felt (Maclean et al., 2021). Additionally, mothers who particularly fear negative judgement tend to feel more guilt around a sense of having failed idealised motherhood (Liss et al., 2013). For example, mothers identify that difficulties with breastfeeding can led to internalised guilt over their “moral obligation” to persevere through the struggles, even at the cost to their own health and wellbeing (Constantinou et al., 2021, p. 864). In research by Palmer et al. (2014), one mother expressed worry over others judging her not to be a real and loving

mother if she did not breastfeed, the authors link these internalised guilt and pressure as a reflection of good mothering standards.

The Future: Social Norms may be Changing

While good mothering norms exist, mothers have navigated, adopted and contested them in varying ways related to other social roles and intersectional identities (i.e. mothers within various classes, sexualities, ethnicities, disabilities and educational levels) (Schmidt et al., 2023). Researchers argue that current inconsistencies in the ways mothers adopt or reject these existing norms is evidence of the possibility of slowly changing norms of motherhood in WEIRD countries (particularly evidenced by relatively newer expectations for 'The Working Mother') (Schmidt et al., 2023). Potential evidence for changing norms is valuable considering researchers argue that this western model of good motherhood needs to be challenged considering the potential risks for "both isolating and overburdening women" (Budds, 2021, p. 1). Australian researchers have called for interventions to unravel the pervasive nature of good mothering ideologies in western societies (Sonnenburg & Miller, 2021). Such interventions should promote flexible and relatable ways of mothering that display the diversity of maternal roles in parenting (Sonnenburg & Miller, 2021). For example, mothers with peer groups that endorse the working mother norm felt less guilt when working away from their children (Maclean et al., 2021). Additionally, parents who actively challenge good mother norms report more having a more positive relationship with their partner (Williamson et al., 2023). Further interventions may include strengthening maternal social support systems (Budds, 2021) and promoting the power of mother's self-compassion (Choma et al., 2024; Miller & Strachan, 2020).

2.3 Section Three: Long COVID in Motherhood

There is relatively little research that is directly on the topic of long COVID in motherhood, especially in Aotearoa New Zealand. However, there is plenty of research that points to impact of other chronic illnesses in motherhood. Three theories (matresence, biographical disruption, and maternal social role conflict) are discussed in this section. A discussion of matresence provides context for motherhood as a unique and particular life stage whereby a maternal identity develops. The life phase of

matresence forms a background upon which the biographically disruptive nature of chronic illness may pose social role conflicts. This section also considers literature on mothering during the COVID-19 pandemic and the current state of literature on long COVID in motherhood.

2.3.1 Matrescence: A Life Stage and Identity Transition

The transition to motherhood is often described as an intense period of physical and psychological change, even to the extent of blurred body boundaries between mothers and children (Stumpfögger & Panagiotopoulou, 2021). Researchers have coined the transitional life stage of becoming a mother as '*matrescence'* (Raphael, 1975), which is similar in concept to the life stage transition of adolescence (Athan, 2024). The transitional stage of matresence highlights the physical, psychological and emotional evolution that mothers experience, often described as a "significant transformation" (Bissell, 2023, p. 1). The significance of this can be evidenced in the structural brain changes that correspond with matresence, which is understood as a new neurocognitive developmental period (Callaghan et al., 2024; Orchard et al., 2023). The concept of matresence centralises the impact of this transitional stage on the mother herself, and how her biological and psychological transformations meet with her new social caregiving role (Callaghan et al., 2024; Orchard et al., 2023). Thus, conceptualising the phase of mother-becoming as a life-wide transition, matresence offers a holistic understanding of what it means to become 'mother'.

This transformation of mother-becoming also requires a process of unbecoming, whereby a woman's sense of self prior to motherhood is remoulded into a new identity (Bissell, 2023). The negotiation of new maternal identities and the loss of previous ones encompass this often complex and demanding life period (Williamson et al., 2023). Australian research indicates that the transition to motherhood has a profound impact on identity, whereby the role as mother supersedes all others (Hansen, 2020). A transitioning sense of self is often described as an emotional experience, and research highlights that the break-down of former identities occurs until mothers adapt to their new role incorporating the presence of new children into their identities (Laney et al., 2015; Reveley, 2019). Only once these phases of identity deconstruction and reconstruction are attended to, can mothers begin to look beyond and consider other

social identities outside of motherhood (Reveley, 2019). Thus, complex identity changes corresponding with motherhood identify this life stage as both complex and demanding (Laney et al., 2015).

Matrescence may be an important theory for conceptualising experiences in motherhood considering its holistic approach to maternal wellbeing, specifically within its nine life domains (biological, psychological, social, cultural, economic, moral, existential, ecological and spiritual (Athan, 2025). Therefore, attention to the domains within matrescence may be important for a comprehensive approach to understanding and supporting the lived experiences of mothers (Athan, 2024).

2.3.2 The Disruption and Conflict of Social Roles

Chronic illness can be understood as life changing event, specifically through the lens of biographical disruption (Bury, 1982). Biographical disruption outlines how chronic illness poses as a disruptive force within an individual's everyday life, including their understanding of themselves and the world around them. This framework outlines three aspects of the disruptive process over time; that is from the onset of illness, disruption to routine lifestyle/identity and how the individual responds (Bury, 1982).

Foundational research by Thorne (1990) furthers the idea of disruption by conceptualising the challenges of chronic illness within the life stage of motherhood. Specifically, motherhood and chronic illness can be considered as a conflict of social roles (Thorne, 1990). This conflict arises when the social obligations of motherhood and those of a chronically ill person collide (Thorne, 1990). Thorne (1990) describes the social obligations for mothers to be inherently and completely self-sacrificial, dependable and responsible. However, chronically ill people experience the social obligation to fully "accommodate one's life to the illness" (Thorne, 1990, p. 218). Thus, mothers' expectations to self-sacrifice are inconsistent with expectations of chronically ill people to enact self-care. It is the ways that the roles of 'being ill' and 'being mother' have been socially constructed that conflict with one another, and this conflict poses challenges for mothers living within this complex space (Thorne, 1990).

Many examples of research have applied the concepts of disruption and conflict of mothering roles amidst various illnesses, these include chronic fatigue syndrome

(Donalek, 2009), HIV infection (Wilson, 2007), kidney disease (Cluley et al., 2023), multiple sclerosis (Parton et al., 2019; Parton et al., 2018), breast cancer (Mazaheri et al., 2021), cystic fibrosis (Barker et al., 2017), depression and diabetes (Potter, 2024). For example, (Vallido et al., 2010) conducted a narrative synthesis of literature of mothers' experiences with a range of chronic illnesses including mental illness, cancer, HIV/AIDS, and inflammatory arthritis. They found that mothers with these chronic illnesses experience a disruption in their abilities to mother their children (Vallido et al., 2010). Mothers experience significant social and emotional distress at the negative impacts that falling ill had on their abilities to take part in childcare responsibilities (Vallido et al., 2010). For example, women highlight how cancer distanced them from being able to enact their mothering role, and its associated daily responsibilities (Dorgan et al., 2013). This disruption of "mothering performance" by illness subsequently left mothers questioning their mothering abilities and if their physical inadequacies had squandered their abilities to be good mothers (Dorgan et al., 2013, p. 67). Attending to the needs of being an ill person (e.g. attending medical appointments and treatments) added to a sense of impeding upon their mothering role (Dorgan et al., 2013). That is, the performance of the sick role conflicted with mother roles. This is linked to social expectations that mothers care for others and are not mothered themselves (Dorgan et al., 2013).

Therefore, researchers highlight that further research on the intersections between chronic illness and particular life contexts (e.g. motherhood) are important for producing knowledge that has direct application to everyday living (Thorne, 1990). This is specifically important considering the historical approach to considering chronic illness experiences as gender neutral, and thus context independent (Thorne et al., 1997). Topical applications of these theoretical concepts are discussed in the next sections: *2.3.3 Mothering within the COVID-19* Pandemic and *2.3.4 Experiential Elements of Long COVID in Motherhood*.

2.3.3 Mothering within the COVID-19 Pandemic

Women in countries belonging to the OECD (The Organisation for Economic Co-operation and Development) are responsible for approximately 75% of the unpaid care work within communities (Moreira da Silva, 2019). However, with the onset of the

COVID-19 pandemic, research from the United Nations has shown that this care burden has increased for women via school closures, increased healthcare needs and work from home policies (United Nations, 2020). In this way the COVID-19 pandemic has contributed to exacerbating the inequalities in gendered care across OECD countries (United Nations, 2020). The burden of household and caregiving work has been labelled the "gender care gap" (Hennecke, 2022, p. 4). UK research has explored the experiences of the "mobilisation" of mothers out of workplaces and back into homes to care for children all the while continuing with their paid work obligations (Ashman et al., 2022, p. 1126). Mothers' experiences were characterised by the reorganisation of their lives to prioritise both work and caregiving via the mandated compliance required by the government (Ashman et al., 2022). Research from the US highlighted that the pandemic caused "an overall increase in domestic responsibilities for mothers who were already doing most of the household labour [prior to the pandemic]" (Carlson et al., 2022, p. 1). Research has also shown that the COVID-19 pandemic has resulted in increased family responsibility and care work for single mothers as well (Pino Gavidia et al., 2023). Researchers call for recognition of the often-invisible labour provided by women in homes and communities in order to address the pandemic's gendered care divide (Power, 2020).

With the turn back to traditional gender roles in the home during the pandemic, researchers highlight that neoliberal mothering norms were further intrenched (Güney-Frahm, 2020). Researchers have drawn upon the language of "maternal responsibilisation" to define the call for mothers to be primarily responsible for the needs of their children during the COVID-19 pandemic and across other widespread crises (Paterson et al., 2025, p. 4). Research has shown that during the pandemic mothers endorsed the expectations placed upon them to be autonomous, responsible, self-sufficient, self-sacrificial and fully child-centred (Dudová, 2025). Research by Orchard et al. (2025) explored the experiences of mothers caring for their children during the pandemic. Mothers experienced continual demands and pressures to self-sacrifice their own care needs for their children which created a heavy toll on their emotional wellbeing, mothers described the experience as "not getting a break [and] being stretched thin" (p. 7). The poor mental health impacts experienced by mothers

from increased childcare burdens, has been identified by many researchers (Fisher et al., 2024; Hoppen, 2023; Jin & Murray, 2023; Loughman et al., 2021; Sentieiro et al., 2025; Yakub et al., 2024; Zhou et al., 2024).

In New Zealand, research on mothers' experiences during the pandemic has highlighted the significant emotional toll that came with the increased worries and management of homes and families (Thorpe et al., 2024). Similar to international literature, New Zealand mothers experienced the inequalities in the division of household labour, whereby they participated in a greater share of home and child work compared to fathers, which contributed to poor mental health and relationship dissatisfaction (Waddell et al., 2021). Additionally, New Zealand mothers living with chronic illnesses (e.g. chronic pain, fibromyalgia and chronic osteoarthritis) during the COVID-19 pandemic experienced emotional exhaustion around the uncertainty and risk of living for multiple years living with the heightened responsibilities of caring for themselves and others (Thorpe & O'Leary, 2025).

2.3.4 The Challenges of Long COVID in Motherhood

While the current understanding of how mothers experience long COVID is not comprehensive, numerous studies have identified motherhood as a particularly challenging context. It is important to note that most existing research does not explicitly focus on mothers, instead research includes participants who also happened to be parents. Of the research discussed, only three studies explicitly focused on the lives of mothers and/or parents with long COVID (Quirke et al., 2025; Schröder et al., 2024; Silletti et al., 2025). This likely underestimates the depth and breadth of challenges that mothers may face with this illness. Therefore, there is a research gap for studies that provide detailed qualitative analyses of mother's experiences with long COVID.

Physical Impacts

Many people with long COVID, mothers included, discuss the life changing and disruptive impacts of falling ill (Wasilewski et al., 2025). Recent research has shown that people with long COVID adapt to or limit participation in various social roles after falling sick (e.g. work, study, hobbies) (León-Herrera et al., 2025). However, parents

childcare responsibilities largely remain despite illness, and research shows that mothers in particular feel pressure to fulfil their childcare duties (León-Herrera et al., 2025). Research highlights that parents with long COVID have reported challenges in the management of daily responsibilities, such as caring for children and housework (Quirke et al., 2025). Quantitative research from Schröder et al. (2024) found that people with long COVID faced greater difficulties in their parenting tasks compared to people without the illness. Fulfilling expectations to continue childcare despite struggling with symptoms is often described as a stressful, frustrating and emotional experience (Aghaei et al., 2022; Schröder et al., 2024). Challenges in mothering are often linked to functional impairments from long COVID symptoms, namely fatigue and brain fog (León-Herrera et al., 2025; Smith et al., 2025b). These symptoms become a significant barrier for completing household tasks such as laundry, dishes, cooking and taking children to and from school (Schröder et al., 2024; Smith et al., 2025b; Spence et al., 2023).

Social Impacts

The coupled burden of illness and parenting has also been associated with a reduced capacity for socialisation and leisure activities (Schröder et al., 2024). In most circumstances, mental and physical energy were only available for completing daily home and childcare routines, and anything outside of this was extremely limited (Schröder et al., 2024). Parents with long COVID report managing their energy availability in order to prioritise their daily tasks, including reserving energy specifically for childcare (Chasco et al., 2022). However, for working mothers, energy was often used up in the workplace which left little for entertaining children in the evenings (Chasco et al., 2022). Reduced capacity for socialisation is worrying considering the positive benefits mothers reported that parenting routines had for reducing feelings of social isolation and enhancing mental health (Schröder et al., 2024).

Emotional Impacts

Research shows that mothers' awareness of the impact their sickness has on the family unit and their inability to enact their mothering role led to feelings of guilt and inadequacy (Smith et al., 2025b). Mothers have also reported that children modify their behaviour due to worries about worsening their parent's illness (Smith et al., 2025b). It

has been identified that when children often step up to help care for parents and take on more household responsibilities, parents are often left feeling guilty (Chasco et al., 2022; Smith et al., 2025b; Wasilewski et al., 2025). This is particularly the case for solo mothers who often rely on friends, family, older children and/or paid help in the home (Wasilewski et al., 2025).

Difficulties in mothering children due to long COVID seems to be an emotional experience and mothers have reported a sense of lost maternal identity due to their inability to take part in activities with their children (Ryan et al., 2025). Pressures that mothers face to fulfil their caregiving roles have been understood as a response to the social expectations for good mothers to "embody traditionally feminine qualities such as nurturing" (León-Herrera et al., 2025, p. 11). Pressures to uphold mothering standards amidst long COVID have led some mothers to understand their struggles as source of personal and moral failure (McDuff et al., 2025). In these ways, a sense of maternal inadequacy during the long COVID experience may negatively impact maternal independence, pride and sense of self (Spence et al., 2023; Wasilewski et al., 2025).

Considering the emergent state of research, the unique responsibilities and social expectations in motherhood seem to pose additional challenges for those living with long COVID. However, detailed analyses of mother's lived experiences are lacking amidst the existing corpus of literature.

2.4 Summary

The existing literature on long COVID highlights significantly debilitating impacts on quality of life. Multiple life domains are impacted which include functional limitations to mobility and cognition; difficulty maintaining social and work lives; poor mental health and negative sense of self. Current literature on the intersections between long COVID and motherhood suggest that mothers may face additionally difficult experiences living with this chronic illness on top of their childcare and mothering responsibilities. Although the literature specifically on mothering with long COVID is limited, it is suggested that this illness has compounding challenges. Specific literature highlighted above shows that motherhood is a complex time of physical and

psychological change that exists within a culture of expectations and norms regarding what constitutes 'good' vs 'bad' motherhood. Understanding the unique intersections between long COVID in motherhood is important to highlight the physical, emotional and social needs of mothers dealing with the complex challenges of this new chronic illness. The next chapters outline this thesis project and how this research can contribute to the existing literature on long COVID in motherhood to guide future research and potential directions to support mothers living with this illness.

CHAPTER THREE: Methods

This chapter outlines the methodology and procedure of this thesis project. The epistemological assumptions behind the chosen methodological approach are discussed along with its suitability for research into long COVID within the life context of motherhood. Recruitment, participant characteristics and interviewing practice are also detailed along with the data analysis procedure and ethics. This thesis project employed exploratory qualitative methods guided by a foundation within the psychology of health and illness. The epistemological and methodological standpoint of Interpretative Phenomenological Analysis (IPA) provided the foundations for this project along with the method of online semi-structured interviews.

The creation of quality research is important for contributing trustworthy and valued knowledge to the existing body of literature. Quality within qualitative research can be shown throughout the research design through a purposeful commitment to various criteria, such as rigor and richness; sensitivity to context; an ethical approach; and displaying transferability and impact (Cena et al., 2024). Additionally, researchers have also attempted to elucidate ways to do this within the methodological commitments of IPA (Nizza et al., 2021). Specifically, Nizza et al. (2021) has outlined four criteria to establish quality within IPA which include the creation of a compelling narrative, vigour within experiential accounts, specific attention to the participant's words during analysis and addressing converging and diverging lived experiences. Considering these general recommendations for producing quality research, I have approached the production of this thesis with these in mind and discussed these throughout this methods section.

3.1 Methodological Principles

I employed the principles and analytical procedures of interpretative phenomenological analysis (IPA) in this thesis project (Smith et al., 2022). IPA is grounded within the philosophy of phenomenology and hermeneutics which together provide strong methodological commitments for exploring experiential phenomena through an interpretative lens (Eatough & Smith, 2017). IPA is committed to a detailed

analysis of participant's lived experiences while also acknowledging space for idiosyncratic and common elements (Eatough & Smith, 2017).

IPA has a strong history within health psychology research (Brocki & Wearden, 2006; Smith, 1996, 2004; Smith et al., 2013). Specifically, the exploration of illness experiences constitutes the largest corpus of existing IPA literature (Smith, 2011). It can be argued that IPA pairs well with a focus on illness experiences due to its strengths for dealing with experiences that are significantly transformative or important to the participants, thus inspiring reflection, interpretation and meaning making (Smith, 2004). Essentially, IPA is useful for experiences that matter to the participants which in turn can influence how they view themselves and their place in the world. Thus, IPA is well suited to the study of illness experiences whereby participant's sense of self and identity are impacted (Eatough & Smith, 2017). For these reasons, I approached this thesis utilising these strengths to provide a multi-layered interpretative analysis of the lived experiences of mothers with long COVID.

IPA grounds its theoretical foundation within three specific philosophical components: phenomenology, hermeneutics and idiography (Smith et al., 2022). Therefore, these features that have formed the epistemological foundation of this thesis and are discussed below.

3.1.1 A Phenomenological Perspective

Phenomenology encompasses a group of philosophical approaches to the study of experience which was pioneered by the works of Husserl, Heidegger, Merleau-Ponty and Sartre (Smith et al., 2022). IPA's approach to phenomenology moves beyond the original descriptive orientation to phenomenology that sought the real "essence" behind what constituted an experience (Shinebourne, 2011, p. 24). Instead, IPA utilises an interpretative phenomenological perspective to focus on the meaning of lived experience for individuals embedded in particular life contexts (Shinebourne, 2011). This phenomenological approach aims to delve into the phenomenon of interest, specifically as it is lived by the person that is experiencing it (Eatough & Smith, 2017). Therefore, experience is understood to be a personal perception rather than a singular or objective truth represented by the experience (Smith, 1996). This personal nature of

experience means that they should be analysed on their own terms, with participant's language and without prior theoretical frameworks imposing upon the participant's lifeworld (Smith, 2017). In keeping with an interpretative phenomenological lens, this project did not utilise pre-defined theoretical frameworks prior to the analysis of participant's stories, so that their lived experience can be seen on its own terms. Additionally, to acknowledge the participant's personal interpretation of their experiences, analysis and reporting of the findings utilised the participant's own language as much as possible.

3.1.2 Hermeneutics, Interpretation and Making Meaning

The second epistemological element within IPA is the philosophy of interpretation, also known as hermeneutics (Smith, 1996). Originally a method for interpretating ancient historical texts, hermeneutics flavours the phenomenological perspective to become one invested in the interpretation of experience (Shinebourne, 2011). Interpretation is a necessary component for the exploration of lived experiences because IPA does not consider experience as an objectively accessible phenomenon (Smith et al., 2013). Instead, an experience can only be accessed through the interpretation and meaning-making activities of people. A key assumption within IPA is that people are inherently sense-making individuals as they reflect upon the experiences that they have in the world to find meaning (Smith, 2019). It is this meaning that is essential to understanding the experiences themselves and is a central feature of IPA research (Smith, 1996).

These meaning-making and interpretive processes are not just from the perspective of the participant, but also the researcher. This dual aspect of interpretation is known within IPA as the double hermeneutic (Smith, 2019). The double hermeneutic frames the researcher-participant relationship, as both are engaged in a process of mutual interpretation when in conversation (Smith, 1996). Specifically, Smith (2004) describes this process as "*the participant is trying to make sense of their personal and social world [while] the researcher is trying to make sense of the participant trying to make sense of their personal and social world*" (p. 40). Thus, meaning is only elucidated from an experience when it is bound within both the participant's and researcher's life contexts (social, political, economic, historical, personal etc.). In this thesis, each of

the participant's interviews were analysed individually considering their unique life contexts and the impact that these inevitably have upon their lived experiences as mothers with long COVID (e.g. family, socio-economic status, and parenting dynamics).

An important feature of interpretation is that both participants and researchers cannot engage in the interpretation of an experience without bringing into the process their own presuppositions and personal contexts (Shinebourne, 2011). The ways people make meaning from their experiences is embedded within their personal histories and life worlds (Eatough & Smith, 2017). Balancing between the individual and the context, or the 'part' and the 'whole', is what allows for the exploration of meaning within accounts of an experience (Eatough & Smith, 2017). This is known as the hermeneutic circle, whereby the interpretation of meaning acts like a dance between the particular and its context (Eatough & Smith, 2017). In this way the participant's and researcher's life worlds are inherently present within the sense making of any IPA project. The subjectivity of interpretation is not viewed within IPA as negative bias, but as an inherent feature of people trying to understand people (Eatough & Smith, 2017). In this thesis, personal reflexivity was important to outline how I have approached the research process considering my own life context and the impact of this upon my position of interpretation (please see the section titled '*3.6 Research Transparency*' for a discussion on reflexivity).

3.1.3 An Idiographic Approach

IPA is not just interested in the interpretation of lived experiences in a general sense, but for particular people (Smith et al., 2022). The participant's themselves are considered central and careful attention is given to the phenomena of interest particularly as it is experienced in the participants lived world (Smith et al., 2022). An idiographic approach provides value by first attending to the details of the individual and using these to add richness to our understanding of group-level experiential elements (Eatough & Smith, 2017). This allows for the researcher to hold space for the complexities and variabilities that exist within each individual (Eatough & Smith, 2017). Through a commitment to the idiographic, IPA is not focused on the establishment of generalisations across a large group of people, but rather the detailed experiential

accounts of particular people in their individual situation (Smith et al., 2022). Therefore, this thesis does not aim to provide generalisable findings that can be extrapolated across all mothers in New Zealand with long COVID, rather this thesis aims to detail the particular experiences of the participants involved.

Idiography manifests in one of the key assumptions behind IPA, which is that the participants are seen as experts on their own lived experiences (Eatough & Smith, 2017). Therefore, careful attention to the ways participants made sense of their personal experiences, including their language use, was important in this thesis to acknowledge their expert position. IPA's idiographic commitments were also shown in this thesis by the use of small samples and firstly attending to the individual's stories before analysing across common or divergent elements at a group level (Smith et al., 2022). Additionally, this thesis utilised IPA's focus on first-person experiential accounts to produce detailed and nuanced accounts of the meanings made from lived experiences (Smith et al., 2022). By attending to the idiographic nature of lived experience, this thesis aims to provide a detailed analysis of both similarities and differences in the participant's lived experiences of long COVID in motherhood.

3.2 Recruitment

The participants for this thesis were recruited through New Zealand's Long COVID Registry which runs through the University of Auckland (University of Auckland, n.d.). The registry is the only one of its kind in the country and was set up to provide an overview of the burden of long COVID in New Zealand and hosts 1,342 registry members as of 31st March 2024 (Lorgelly et al., 2024). The registry has an existing process allowing researchers to apply for access to those registered, with approximately 95% of its members consenting to being contacted regarding future research opportunities (Lorgelly et al., 2024). I contacted the registry to circulate my study's advertisement (See Appendix A) after seeking permission from the registry.

In accordance with IPA methodology, my recruitment procedure employed purposive homogenous sampling to gather a cohort of mothers living with long COVID. However, aiming for a homogenous sample was balanced with the unknown availability of mothers within the registry that would fit my inclusion criteria. For example, I hoped

for participants who had long COVID diagnoses, but were prepared to include those with self-diagnoses considering 36-42% of people in the registry do not have a medical diagnosis (Lorgelly et al., 2024). I initially aimed to recruit six mothers, but I ended up with five which is considered sufficient for a master's level theses considering the in-depth analysis required for quality IPA projects (Smith et al., 2022). A small sample allowed my project to maintain a strong idiographic commitment to the detailed accounts of the participant's lived experiences. Additionally, mothers with at least one child under five years old were sought, this was because mothers with at least one child of similar age were considered more likely to have similar experiential elements. However, to achieve the desired five participants, this age was increased to at least seven years old due to recruitment constraints. Attention to detail within the recruitment phase was important for enhancing the quality of data that was generated during the interviews, thus contributing to the quality of this research (Smith et al., 2022).

3.3 Participants

Five participants were included in this thesis. Please see Appendix B for the inclusion criteria within the information sheet. People from all ethnicities were invited to take part in this research, however those who were interviewed all identified as New Zealand European. Considering 85.8% of the registry's members also identified as New Zealand European (Lorgelly et al., 2024), this result was not unexpected. The New Zealand Long COVID registry was purposive in its inclusivity towards recruiting Māori members under a Kaupapa Māori framework, but only 8.6% of the registry identified as Māori (Lorgelly et al., 2024). Considering the often under representative proportion of Māori within health data sets (Harris et al., 2022), this result speaks to the health and access inequities faced by Māori within New Zealand. Future research should seek the lived experiences specifically of Māori mothers with long COVID, as this would be advantageous to address the research gap.

For a summary of participant characteristics please see *Table 1.*

Table 1

Participant Characteristics

Pseudonym	Age	Ethnicity	Children: Age	Parenting situation	Symptoms	Diagnosis Y/N	Time since diagnosis
Anna	38	NZ European	Three: 2-8 years old	With a partner	Fatigue, brain fog, sensory sensitivities	Y	Three years
Freya	41	NZ European	Five: 5-27 years old	With a partner	Fatigue, brain fog, skin condition	Y	Three years
Chloe	40	NZ European	One: 6.5 years old	With a partner 3 to 4 days per week, otherwise a solo parent	Fatigue, migraines, pain	Y	Three years
Jane	37	NZ European	One: 1.5 years old	With a partner	Fatigue, brain fog, nausea, pain	Y	Three years
Emma	44	NZ European	One: 7 years old	Initially solo parenting, but parenting with a partner at the time of the interview	Fatigue, migraines, pain	Y	Three years

3.4 Procedure

Members of the New Zealand Long COVID registry were emailed the study's advertisement, information sheet (Appendix B) and were invited to participate in this thesis project. Eleven potential participants contacted me from the registry and seven met the studies inclusion criteria. Six potential participants took part in an introductory phone call to discuss the nature of the study and clarify any questions regarding taking part. These participants completed a consent form (See Appendix C) and were given a copy of the interview schedule (See Appendix D) at this time so they could review the interview questions prior to the conversation itself. Of these, five were interviewed and one declined to participate.

The semi-structured qualitative interview was utilised for this research project which is a widely established approach within phenomenologically based research (King et al., 2019). The semi-structured interviews followed an interview schedule which guided the conversation within the context of the intersections between long COVID and motherhood (see Appendix D for the interview schedule). In keeping with IPA's focus on the individual's personal lived experiences and how they make sense of these (Smith, 2004), I approached the interview in a flexible way to allow for each participant to guide our conversation to what was important for them. In this way, a participant-led approach to the direction of discussion within the interview was important for generating rich and detailed experiential accounts that were important for each participant to discuss, thus contributing to vigour and richness in IPA research (Nizza et al., 2021).

Each participant was invited to either a single 1.5 hour or two 45-minute interviews online via Zoom. Flexibility for participants to choose single or multiple shorter interviews was important considering that fatigue and brain fog are among the most common symptoms of long COVID (Santoro et al., 2025). Participants were given the autonomy to choose which interview option best suited them, and one participant opted for the two shorter interviews, the other four participants were comfortable to partake in a single longer interview. Participants were reminded of the opportunity to take breaks at any time during the interview; however, none felt the need to do this. The

choice for interviewing online was important to increase accessibility for participants located throughout New Zealand and also to reduce time and transport burdens for busy mothers also coping with various intensities of long COVID symptoms. Consent was obtained in written form (Appendix C) and verbally during the phone call and interview(s).

Interviews were audio recorded through the Zoom application and converted into a transcription document through Scribesound.com. Participants were given the opportunity to have a copy of their interview recording for personal purposes, one participant accepted this. Transcripts were edited to remove personally identifying names and places and participant names were replaced with pseudonyms. Participants were given the opportunity to review their transcripts and edit their language to ensure the interview represented their experiences in a way they approve. One participant agreed to receive their transcript, but no participant wanted to make any changes. Participants noted the cognitive burden of reading a long document considering their current symptoms of fatigue and brain fog and instead were happy to not review their transcripts. All participants received a $50 online Prezzee voucher as a token of appreciation for their time and stories.

3.5 Ethics

Full ethical approval was sought for this project considering the potential for participant's psychological distress when discussing personal and sensitive experiences with their health and families. Attention to ethical decision making was important throughout the entirety of this thesis; strong ethical commitment is a hallmark of quality in research (Cena et al., 2024). Ethical approval was granted by the Massey University Human Ethics Committee on 13/05/25 for Application OM1 25/29. The ethical principles followed in completion of this thesis include those discussed below along with Massey University's Code of Ethical Conduct for Research, Teaching and Evaluations Involving Human Participants (Massey University, 2017).

3.5.1 Informed Consent, Confidentiality and Privacy

All participants were provided with a participant information sheet outlining the details of the research prior to digitally signing a consent form. Informed consent was

furthermore approached as a continual process throughout the project and participant approval for participation was repeatedly sought during the introductory phone call and at the beginning of the interview(s). At these times participants were encouraged to ask questions to clarify any part of the process. In this way, participants ability to consent to the project was monitored throughout their involvement.

Participants were also reminded in the introductory phone call and interview that they were able to withdraw completely at any time, as well as taking a break or postponing the interview for any reason. During the interviews I monitored participant distress, and at times of particularly emotional experiences (three participants became emotional) participants were given the opportunity to take a break. However, none accepted and instead participants felt okay to continue conversing. In these and other emotional moments, there were times I decided not to follow up with further questions and instead slowly led the discussion elsewhere to avoid perpetuating any potential distress. Other than these specific moments, participants generally felt comfortable and open to share their personal experiences.

Participants were made aware of their rights for confidentiality and privacy within their information sheet. In accordance with these rights, all identifiable information within their transcripts were removed (family names, locations and former workplaces) and participant names were replaced with pseudonyms to keep their identities private. The master pseudonym record was kept separate from all other participant information and will be deleted after assessment of this thesis.

Documents with participant identifying information (consent forms, participant contact information) along with deidentified transcripts were stored separately for the duration of the project and will be stored by my supervisor for five years after the assessment of this thesis and then destroyed. All recordings taken of the interviews were used to make written deidentified transcripts and were immediately destroyed.

3.5.2 Participant Autonomy and Respect

Acknowledgement of the participant's rights for dignity, autonomy and respect were pivotal to my research approach. Participants were given choice at each stage of the data collection process to honour their personal needs. For example, participants

had the opportunity to have the interview at any time/day of the week to acknowledge their caregiving commitments and time availability. Online interviews were also chosen to increase the accessibility of the project for mothers throughout the country and with varying intensities in their long COVID symptoms which may have been a barrier for participating in in-person interviews where travel was required. Additionally, participants were given options to break up their interview session into multiple smaller sessions as a method to protect their energy and fatigue levels, one mother did take the opportunity to break up her interview into two shorter sessions. I considered this adaptable approach to interview accessibility important considering that fatigue and brain fog are among the most common symptoms within long COVID (Santoro et al., 2025).

Through an adaptable approach to participant interactions, I was able to honour their needs and respond in a way to minimise potential distress. Distress was further minimised by excluding any potential participants currently receiving treatment for post-natal depression which could have been triggered and/or exacerbated during the personal reflections needed for a discussion of their health experiences with long COVID. All participant interactions were conducted with an empathetic and non-judgemental approach, to minimise the potential for psychological distress and respect participants stories and their willingness to discuss sensitive and personal information with myself. Considering the interviews discussed personal and sensitive experiences, it was important that I led the discussion near the end with a more positive and light-hearted tone. I did not want to end a potentially emotional discussion abruptly, so this was where I asked the participants about their favourite motherhood memories and I made an effort to transition gradually to the end of the interview.

Additionally, participants were contacted prior to submitting this thesis to give feedback on potential titles, particularly for the quote that appears within the title. Participants were asked which quote from a range of options that they felt best represented their overall experience. I felt this consultation was important to respect the centrality of the participants and their experiential expertise that have made this thesis possible.

3.5.3 Cultural Considerations

All research within New Zealand should show commitment to Te Tiriti o Waitangi and show cultural consideration for research with Māori and Pasifika ethnic groups. For this project this meant that consultation with a cultural advisor within Massey University's Department of Psychology was necessary for guidance and support to create a project in alignment with the cultural needs for potential Māori participants and specifically, adherence to the Te Ara Tika Guidelines for Māori Research Ethics (Hudson et al., 2010).

To uphold the dignity and mana for Māori mothers who may have participated in this project, it was important I did not assume their relational and cultural needs, which would instead be discussed on an individual basis. Providing space for sufficient whanaungatanga (relationship building) via multiple contact points (emails, introductory phone calls and the interview) were recognised as important conversation-based relation building practices. Additionally, mihi/pepeha (introductory greetings) and karakia (prayers)/whakataukī (proverbs) were prepared and available at the start of the interviews with Māori participants who were interested. If Māori mothers were to provide unique experiences that may highlight inequalities in long COVID supports and/or mothering treatment as opposed to non-Māori mothers, it was important that approach these stories with inclusivity towards Te Ao Māori and Mātauranga Māori (Māori knowledge). Respect for tikanga (Māori customs) was a foundational aspect of my cultural considerations, particularly the notion of reciprocity as expressed through a koha (gift) to recognise the participant's time to share their stories. Ongoing consultation with my cultural advisor was expected if Māori mothers expressed interest in participating in the project. As mentioned, no Māori expressed interest in this research but reflecting upon these issues was relevant for myself considering that relational ethics was important for respectful communication with all participants.

3.6 Research Transparency

Research transparency is essential to allow readers to evaluate the claims, and therefore quality, of the research by having visible access to the processes underlying its design, methods and analysis (Moravcsik, 2019). To honour the value of transparent

research, records of research decision making, reflections from interviews and details throughout the analysis process were created to act as a paper trail to document this project in an open and honest way. Excerpts of my work have been provided as evidence of my research and decision-making processes (please see Appendices D to H for copies of my interview schedule, exploratory noting/statements, PETs, GETs and excerpts from my reflection diary).

Positionality and Reflexivity

As a young university educated New Zealand European woman without children or lived experiences of long COVID, my outsider status was an ever-present context for how I entered the research and knowledge development process. Engaging in continual reflexive practice throughout the research was essential to acknowledge my positionality and the inherent influences this had on the co-production of knowledge with the participants. The process-like approach to reflexivity acknowledges that reflexivity not as a task to achieve, but a way of being within the research process and its data (Engward & Goldspink, 2020).

Despite the inherent lack of personal knowledge of the experiences at hand, the outsider positionality can be helpful for enhancing sensitivities to previously taken for granted experiential elements that insiders my overlook (Hayfield & Huxley, 2015). This allowed me to attend to the idiosyncrasies of the lived experiences expressed by the participants without imposing my own presuppositions of what motherhood or long COVID 'should' look like. As an outsider, I intentionally approached my participants as experts in their own lived worlds by mirroring their language and ways of making sense of their experiences. My approach was one of open curiosity and non-judgement. Additionally, semi-structured interviews became a conversational space where participants led the conversation, thus I made participant led data a priority (Milligan, 2016). My approach to acknowledging the outsider positionality helped aid my commitment to the underpinnings of IPA research by honouring the participants as the sole experts in their lived experiences (Eatough & Smith, 2017). For example, upon establishing that I was not a parent myself, one of my participants expressed a struggle to find the "right words" that could explain an element of the experience. While she found her words, I listened carefully and afterwards reflected on the impacts my

outsider status was having on distancing myself from the participant's lived world (See Appendix H for a reflection on this). While my outsider status was unavoidable, it was important to recognise the impacts of this on the research.

While recognising my outsider status, the insider-outsider dynamic is not binary, but fluid (Milligan, 2016). While an outsider to long COVID and motherhood, I shared similar cultural socio-economic and gender backgrounds to my participants, which meant I could empathise in a deeper manner when participants talked to these aspects. These tensions between insider/outsider status influenced the balance of power within the research, particularly the interview process. In acknowledging my predominant outsider positionality, I approached the interviews with the humility to prioritise the participant's authority within the discussion by letting them lead the conversation, thus using my outside position to approach the research process in a way that "deconstruct[s] the author's authority" (Finlay, 2002, p. 2).

3.7 Data Analysis

Analysis of interview data under IPA avoids a prescriptive tick-box- approach (Smith et al., 2022). Instead, IPA generally follows a general set of analytical processes that share a focus on the participant's sense-making within their lived experiences (Smith et al., 2022). By attending to this shared analytical focus, the 'doing' of analysis can maintain commitment to the epistemological underpinnings of IPA while also holding space for creativity, collaboration, interpretation and the overall complexities of doing IPA (Smith et al., 2022). While appreciating the variability in IPA procedures, Smith et al. (2022) offer procedural guidance for researchers new to this type of analysis, and these formed the foundation for my analytical procedures. These are as follows:

3.7.1 Case Familiarisation

The first step involved generating a deep understanding of each individual case within the context of the interview and the participant's lifeworld. This involved creating the initial transcript, listening to the audio recordings while following the transcript, reading the transcript and re-reading again. It was important to note that each participant's transcripts were analysed individually before looking across participants. This process was important to acknowledge the idiosyncrasies of each participant's

lived experiences, meaning making and life contexts. Since initial analytical processes were within each participant's lifeworld, the final analytical product represents a commitment to the idiographic foundation of IPA. My process of case familiarisation aimed to familiarise myself with the participants' unique personal contexts, illness experiences and family and parenting dynamics.

3.7.2 Initial Notes

Once I felt familiar with the content held within the first transcript, initial thoughts/notes/critiques/questions were added line by line to a printed copy of the transcript itself. I created a wide margin document of each transcript, printed these out and added my initial analytical commentary to each sentence/few sentences. Initial notes attempted to adhere to the participant's own meaning making, utilising their vocabulary where possible to stay close to describing what is of importance to the participant. While also adhering to the participant's meaning making, initial notes also added in my own analytical queries such as ("I wonder how x relates to y" or "could z reflect abc?"), potential contradictions in participant's accounts, and points to follow up on were also noted. The result of this step created a deeper sense of understanding of the participant's lived experiences, while forming my first connections between ideas throughout the transcript. Initial noting also converged with underlining/highlighting powerful statements which initially stood out to me and could become quotes within my thesis. These statements were deemed powerful if they seemed to capture a common phenomenon at hand, often summarising a larger concept within the section of transcript.

3.7.3 Creation of Experiential Statements

Once the transcript was explored through the initial noting of experiential elements, I moved towards the formulation of experiential statements (See Appendix E for an example). The experiential statements were written on the left-hand margin of the transcript, opposite the initial notes on the right. Using both my initial notes and the transcript, experiential statements aimed to create a more concise understanding of the experience while also holding to their complexities. This step was where my interpretations of the participant's experiences and meaning making were introduced and thus, the analysis becomes a collaborative effort between my interpretations and

the participant's experiential accounts. This stage of analysis attempted to stay close to the participant's experiential account, while also incorporating a more conceptual understanding based on my interpretations as the researcher also considering the entirety of the interview itself. In this way, the experiential statements aimed to stay close to the participant while also attending to a larger pattern/phenomenon. These larger patterns within experiences were naturally dispersed throughout the transcript, so it was important to consider the transcript as a whole whereby experiential statements connect the overarching ideas throughout, thus this stage of the analysis considers the hermeneutic circle of IPA (Smith et al., 2022).

3.7.4 Identification of Personal Experiential Themes (PETs)

Experiential Statements were then connected to form Personal Experiential Themes (PETs) which grouped similar statements together to comment on an overarching experiential element. To do this, every experiential statement created throughout the printed transcript was copied into the software OneNote, to organise into PETs using a mind-mapping technique. Each PET was digitally moved around on screen to group similar experiential elements together; the result was a page of experiential elements grouped within sections under a heading of the overarching PET. This helped me consider how each element fit together as part of a larger whole, thus attending to the hermeneutic circle within each participant's account. Each participant transcript was analysed individually one at a time using these steps. The result of this was a PET mind map for each participant's transcript (see Appendix F for an example of the PET mind map created for Jane).

3.7.5 Identification of Group Experiential Themes

All PETs were gathered into a new OneNote page to be organised into Group Experiential Themes (GETs). In a similar manner, the PET groupings were digitally moved around on screen to cluster together with other PETs from various participants. PETs that attended to an overarching idea were gathered to form these new GETs, and these included ideas that both converged and diverged, thus offering alternate experiential elements or sense making. The PETs from each participant were colour coded to help me visualise the array of participants who held supporting elements for each GET; this helped me understand the comparative richness between each grouping. The result of

this analytical step created a final mind map of GETs which were used within the writing up of the analysis (See Appendix G for an expert of the GETs mind map).

3.7.6 Writing the GETs into a Narrative

The GETs generated in the previous analytical step were organised into the overarching five themes presented in *Chapter Four: Findings*. The titles for each GET were reconsidered multiple times to capture the core features across the PETs. This step also involved including quotes from participants as evidence for converging and diverging experiences within each theme. The inclusion of both convergence and divergence within the experiential accounts is important to demonstrate idiographic depth across all participants, and this is foundational for acknowledging the individuality and comparability across the participant's experiences (Nizza et al., 2021). A wide variety of quotes from multiple participants were selected to ground the themes within the participant's experiential accounts, personal meaning-making and language. The quotes to be utilised within each GET were considered multiple times so that elements from all participants' experiences were represented within the findings. It was important for me as an ethical researcher that quotes from everyone were included and that no single experience was prioritised over the others. Quote selection was important to reflect the participants' stories and idiosyncrasies within the narrative write up. Sufficient balance between quotes and supporting analysis was important to demonstrate quality research that is committed to a "close analytic reading of participant's words" (Nizza et al., 2021, p. 371). Additionally, weaving participant quotes within analytic commentary and interpretation were important to contribute to the unfolding narrative of how the participants experienced long COVID within motherhood. An unfolding and detailed narrative are both important markers of quality IPA research that signify a rich analysis (Nizza et al., 2021). This process required multiple phases of reading and re-writing of the themes and the findings overall to find balance between interpretative analysis, quotes and the overall narrative. The themes were purposefully organised to create a cohesive narrative starting with themes that introduced experiences primarily with long COVID and then moved towards themes that brought in aspects of mothering. The analysis only stopped when I did the final editing and submitted the thesis.

CHAPTER FOUR: Findings

This chapter begins with a discussion of themes and subthemes that were constructed to capture the participant's experiences of long COVID whilst being a mother (summarised in Table 2).

Table 2

Themes and Sub-themes

Themes	Sub-themes
Theme One: An Uncertain Illness with Invisible Symptoms	• Long COVID Diagnosis: A Lengthy and Uncertain Wait • Invisible Symptoms Mean People Don't Understand • Gaslighting and Psychologisation
Theme Two: Symptoms Impose Lifestyle Restrictions	• Managing Finances and Work: Physical and Mental Struggles • Active Social Lives are Made "Small" • Missing Out on Motherhood: Long COVID "Kind of Stole it"
Theme Three: Mothering Requires an Adapted Approach	• The Physical Necessity for a New Approach to Mothering • Long COVID Mothering Conflicts with Good Mothering
Theme Four: Mothers Experience Pressure to "Push Through" Symptoms	• The Necessity to "Push Through" Symptoms • Fatigue and Self-Sacrifice are Normal: "You're Just a Tired Mum" • The Consequences of "Pushing Through": Energy Crashes and Burn Out
Theme Five: Changing Identity and Self-Reflection	• "Lost Who I Was": An Altered Sense of Self • Self-Reflection and 'Unexpected Positive Learning"

The initial two themes introduce the reader to the participant's experiences with long COVID and the broad lifestyle impacts experienced from the illness. It was particularly important to place these themes first considering most readers may be unfamiliar with this chronic illness and its impacts. The subsequent three themes introduce the reader to specific intersecting elements of long COVID and motherhood. As a reminder, please see Table 1 in *Chapter Three: Methods* for a summary of participant characteristics.

Please note that the term 'COVID' is written without capitalisation and appears as 'Covid' within the quotes from the participants. This is to avoid accidentally implying that participants have emphasised the term.

4.1 Theme One: An Uncertain Illness with Invisible Symptoms

This theme introduces long COVID as a challenging condition whereby all participants struggled with its uncertainty as a new illness with primarily invisible symptoms. This invisible nature of the illness left all participants feeling unseen and misunderstood by medical professionals, family, friends and acquaintances alike.

4.1.1 Long COVID Diagnosis: A Lengthy and Uncertain Wait

All mothers faced lengthy periods waiting for a long COVID diagnosis and they all found this period an overwhelming and prolonged experience. Freya spoke to the prolonged nature of receiving numerous tests and medical checks: "…*exhausting, it was just doctor after doctor, check this, go on this waitlist, have this test.*" The medical uncertainty of long COVID as a valid diagnosis meant that the participants faced many months (sometimes a year), while doctors sought alternative causes. During this time, the participant's symptoms continued to worsen.

> I just kept on getting worse and worse to the point where like it was pretty hard to function…so, it took like almost a year…it took a long time to get to the point where she diagnosed me, and I was just kind of progressively getting worse (Jane).

Participants were left waiting, unsure why they felt unwell and if they would recover. This period of waiting coincided with the continual decline of their symptoms and corresponding dramatic reductions in quality of life.

> We were in a position where I couldn't work, I couldn't function, my husband would have to give up work to look after the kids, but I didn't have a diagnosis...by the end of, like, the yearlong search, it was a relief to get it on paper… because it was getting crazy (Freya).

With worsening symptoms, participants were left unable to work or provide care for their children, relying heavily on partners to step in. However, the lack of a diagnosis left them living with uncertainty over the nature of their sickness and potential for future recovery.

When participants were finally diagnosed with long COVID, they were left feeling validated in their struggles but also hurting from the diagnosis of an illness with an uncertain prognosis, treatment, and future.

> It was definitely validating and I think also probably devastating too...you sort of would actually prefer someone to just say...here's the fix for it, you know, so being told that its long COVID is actually like, cool, you've got this thing that no one really understands and no one knows how to fix, so that's actually devastating (Chloe).

Although confirmed in the legitimacy of their suffering, being told they were sick with an illness that the medical profession knew little about and was currently unable to cure, was a devastating experience. Receiving a diagnosis after a prolonged wait still left the participants lost in uncertainty.

> And when she could not come up with any more tests, she said to me, "well, we've exhausted every other possibility, you officially have long COVID, here's a piece of paper" … when she very first said it, it was more kind of scary, because...like...what is that? And nobody can tell me how long its gonna last, or when I'll be able to get out of bed again" (Freya).

> She officially diagnosed me with long COVID and said, "well we don't know anything about it." So yeah, that's it, that was it. I was expecting some kind of answer to what do I do with this, where to go, but it was just, we don't really know what causes it when it happens, some people have it for years, some people not. So, I left feeling like what now? Where do I go? What do I do? (Anna).

Participants expected that receiving a diagnosis would provide them with directions for how to move forward with their symptoms and seek support. However, finding out they were living with the consequences of long COVID left them with more questions than answers.

> And it was terrifying because there wasn't like a timeframe and there wasn't like oh, if you do XYZ then you'll get better, it was just kind of like this big unknown. I'm getting worse, I'm making this big decision to stop work, and then now what? ...I'm taking all this time off to get better, but like what does that look like? How do I do that? ...it doesn't feel good mentally to just to be like doing nothing all day…so that was really hard. I didn't feel like I had a purpose or like I didn't feel like there was any clarity around like what that journey was going to look like (Jane).

Not surprisingly, living with the uncertainty long COVID took its toll on the participant's mental health as they waited for answers.

The lack of information about the reality of long COVID left participants unsure over their future and if there was the potential for recovery or healing. A lack of information was particularly stressful for two mothers who had long COVID in pregnancy.

> Leading up to [my baby] being born, all the information I was getting given was "this is probably going to make you worse", and so that was increasing my anxiety, the information, I think, and not knowing where the heck you can go and what is the best route or scenario, or what happens then or what happens now, yeah it's just a whole world of unknowns that you have to navigate (Anna).

> There was a lot of anxiety around like, how am I going to cope with this? And will me having long COVID like impact baby and I actually ended up in my second trimester getting Covid again and that was like, terrifying, like I was pretty much like convinced that I was going to have a miscarriage...I definitely was pretty anxious when I was pregnant and I think part of that was long COVID (Jane).

The negativity from the lack of satisfactory medical information and interactions left the participants in a state of stress and anxiety while they navigated this uncertainty. Jane echoed the negativity caused by a lack of hopeful information surrounding long COVID:

"a lot of the information that was out there was like scary…and they were only reporting on all the negative stuff...there's no clarity around what it actually means, and you just hear all these like terrifying things." The abundance of negative information surrounding long COVID left Jane wanting additional support and reassurance beyond the obvious advice to rest.

> Just some sort of somewhere to go to find official, you know, helpful information on like what it might look like, and also like what are some things that you could do that might help, rather than just a generic, rest and look after yourself (Jane).

4.1.2 Invisible Symptoms Mean People Don't Understand

Every participant faced challenges having symptoms that were invisible. The common symptoms of long COVID (fatigue, brain fog, pain and headaches) all exist within their bodies and were therefore invisible to others. All the participants mentioned they would have preferred symptoms that could be seen by others in order to feel seen and understood. Chloe expressed this:

> Because it's an unseen illness, you know, I don't have any physical ailment, I don't have a broken leg...even with things like cancer, you can see that someone is sick. They look really unwell when they're receiving treatment and, and it's also something that people understand...so to have this kind of really vague internal illness where you otherwise look well… I often wished that it was, that I looked unwell or that I had a broken bone or something because then there was some external evidence to everybody of what you were going through (Chloe).

The invisibility of long COVID symptoms left the participants feeling isolated and misunderstood. The internal nature of long COVID symptoms hid the reality that they were sick, tired and in pain. This meant that others could not understand that they were ill, because on the outside, they looked well. Referring to her social interactions, Freya says:

> People are so much more effort now, because they don't understand all the things that go along with the condition... and they get frustrated because you won't just get

> over it… I don't have a cast, or a broken leg, or something to show for it. So, it became very socially isolating as well (Freya).

Emma discusses how it was difficult for others to understand the intensity of her chronic pain without having experienced it personally:

> It's invisible you know and the only part about it is self-reporting and people haven't experienced chronic pain themselves, you know**,** it's just beyond the bounds of imagination. I mean before I had chronic pain, I couldn't imagine it properly, you know, I could try and be empathetic…I guess now I know that it is just life-changing and debilitating, whereas before, I mean I know that intellectually, but yeah, it's different…it's not a surprise to me that people don't understand chronic pain at all (Emma).

The invisible nature of their symptoms meant that participants relied on others to understand and believe them. For these participants an embodied sense of knowing fatigue and chronic pain could only come through a lived experience of it, and without lived experience, a barrier existed for those who could know the nature of long COVID and those who could not.

For some participants, the invisibility of fatigue created a barrier even for their partners to know how they felt. *"And even my husband who has seen the worst of it, like I still felt like even he would think I was taking the piss sometimes"* (Chloe). Similarly, Jane says: *"[My husband] would get frustrated about me being tired and then I would get upset…it's definitely my experience...that he hasn't necessarily been able to understand."*

An understanding barrier was particularly present when the word 'tired' was used to talk about long COVID fatigue. This was because 'tired' came with the assumption that long COVID fatigue was comparable to general everyday 'tiredness' in the common sense. *"I don't know if you've experienced fatigue, but it's different to tired, just so drained, like bone drained"* (Anna). Jane also mentions how long COVID fatigue and general tiredness were incompatible words: *"…saying that I was tired and I was like that's such like not [an] accurate word to describe like the intensity of exhaustion that I'm feeling"* (Jane).

> Nobody really understands how tired, tired is. People would go, “oh everybody gets tired just do some more exercise”, and I’m like no, it's not that kind of tired...this is a different level of tired... this is just next level crazy (Freya).

One participant eventually developed symptoms that meant that she finally had “proof” that she was sick.

> There’s not necessarily something physically wrong with my…body, but my nervous system is dysregulated…so that is a thing, that’s kind of tangible ting that you can explain…like my hair, at one point my hair fell out…so that again while quite distressing was also really validating, I was like, look, like tangible physical like proof that I’m sick (Chloe).

Although distressing, having visible “proof” of her long COVID became a validating experience; people could finally see that she was ill. Similar to the impact of receiving a diagnosis, the development of observable symptoms helped Chloe feel legitimised in her illness struggles.

4.1.3 Gaslighting and Psychologisation

Some participants also recounted experiences of having their illness gaslit by friends, family and medical professionals. Participants felt others belittled the legitimacy of their symptoms by considering them ingenuine and/or a result of laziness. This negatively affected participant’s emotional wellbeing as they compared themselves with others. Chloe and Freya discuss this experience:

> You sort of feel like with this particular illness, and because my main symptom was fatigue, you feel like you’re actually just being a wuss...especially when you’re surrounded by other people who have complex lives and children...so when you’re like “oh look, I’m just really tired”, and you sort of feel like people would think you’re faking it, or you’re just not coping with life… I spoke to another doctor who, again, was just kind of like, “oh, you know, you're probably just a tired mum or, you know, everyone's dealing with shit” (Chloe).

> Long COVID’s pathetic. You’re just not trying, you’re just, you just don’t want to work anymore, and you need to get over it. And I’m like, how, how can you go from being

> so accommodating to one medical issue, but so dismissive of another one?... they don't see how tired I am, they just see me in bed all the time, so its perceived as lazy. I do find a lot of people perceive long COVID as laziness rather than an actual medical thing (Freya).

These participants understood criticism as part of a social perception that having long COVID was to be "lazy" or "a wuss". Since people couldn't understand the intensity of their tiredness, the fact they were lying down often meant they were perceived as lazy. Fatigue was therefore seen as something within their control that made them "pathetic" for not overcoming and in this way, a personal failing.

For Chloe and Jane, others also viewed their fatigue as an emotional rather than a medical issue, this left them questioning the validity of their own experiences. *"Because initially like her saying it was like stress and stuff, I was like is this like all in my head? But it really doesn't feel like it's all in my head and it's getting worse"* (Jane).

> It still just seems like this real like malaise kind of issue… more of an emotional issue than a physical one, because there's nothing physically wrong with you…I'm like, 'oh did I just imagine this whole thing, like have I just been depressed this whole time?'... even I question it sometimes (Chloe).

Emma understood these experiences with doctors who gaslit and dismissed her symptoms as a common experience for women.

> I think just being a woman in general, you know, like the amount of pain from women is not taken seriously…at the time long COVID you know, there was a lot of pushback from people being, "oh nothing, you know, doesn't even exist", you know the doctors didn't really understand it…even though I saw my doctor, there wasn't any advice…I think I could have advocated for myself more, but I was just in such a state, you know (Emma).

Even though Emma could recognise that medical professionals were not taking her pain seriously, she felt too sick to speak up for what she knew she needed. This raised an important feature of the gaslighting experience for those who are currently experiencing debilitating symptoms: the struggle to self-advocate.

For Anna who was left bed-bound for over a year, the uncertainty of having long COVID left her treated like a medical specimen in the eyes of health professionals. This dehumanising experience negatively affected her mental health.

> I often had people say, "I've heard about cases like you, but I've never met one" What do I say to that? Thanks? I don't know, but just the information that is given just produces nowhere to go but down really (Anna).

The dominance of invisible and poorly understood symptoms can be understood as a silent contributor to long COVID gaslighting and psychologisation.

While participants waited to receive medical diagnoses for their symptoms, they were left struggling. Additionally, participants were left to live within the uncertainty of their symptoms, even after receiving a diagnosis, along with the negative social and mental health consequences of not being validated in their struggles.

4.2 Theme Two: Symptoms Impose Lifestyle Restrictions

This theme introduces long COVID as a debilitating illness with lifechanging consequences. All participants faced restrictions in their work, financial and social lives due to the physical restrictions imposed by their symptoms.

4.2.1 Managing Finances and Work: Physical and Mental Struggles

All participants were forced to leave or take an extended break from work because of their long COVID. Depending on the degree that their quality of life was impacted by being ill, some participants gave up work entirely and some were attempting a gradual process of returning to work via reduced hours. For the participants it was not just that they did not want to work, but that long COVID made it physically impossible. Freya says: "w*e were in a position there where I couldn't work, I couldn't functio*n."

For Jane, deciding to give up work was a result of some incidents at her workplace.

> I had some bad… just complete exhaustion moments, like at work and stuff…. I fell down the stairs once because I was like walking down the stairs and I was just so tired that like my eyes just couldn't focus… and I did fall asleep in meetings a few times (Jane).

Jane then tried to work from home but that was not physically possible either.

> It was like a pretty big decision for me to leave, like to stop working as well. But I got to the point where I like physically could not, like even if I was like working from home, like my job's not physical or anything, but just like working from home, just being in front of a screen, even like I just physically couldn't do it (Jane).

Chloe and Emma have both tried different strategies to go to work that were all managed by themselves with little support or understanding from their workplace.

> After about a year of me, dipping in and out of work, like trying to go back to work and then failing, getting off sick again...trying to put a couple of hours a day and then just, just failing constantly at trying to return to work in a self-managed way (Chloe).

At the time of the interview, Emma had just begun a three-week period of stress leave from work.

> I'm on stress leave, work, because it's just become it's become too much, like I am basically having burnout because of the chronic pain, and I can't, I can't anymore. So that's in the last sort of three weeks… I don't know when I'm gonna be able to go back, to be honest (Emma).

Emma also reflected on the lack of understanding by her workplace about long COVID.

> Even the fight for me to just stay at two days a week because of my migraines, it was insane. They didn't want to let me do it…it was basically like this battle where they were like "well maybe you can't do your job properly… maybe we should fire you" type of thing. So, there's no allowances for people, you know, with different medical needs (Emma).

Despite the uncertainty around returning to work in the future, the experience of not working allowed Emma to direct more of her limited energy into being a "proper" parent.

> Being off work is fantastic, like I have got actually energy to interact with [my son] when I pick him up from school, like properly interact and properly spend time with him… cause I think since the Covid my resources are just so limited, like when I can't get my energy, it's like you know, it gets used up (Emma).

For some participants managing their family and finances meant that partners had to stop work as well. Partners were required for support and to take over childcare needs. Anna says: "*eventually it was, no, [my husband] needs to quit his job, so that we don't have to pay for a nanny*."

While the participants lived in varied socio-economic circumstances Freya and Anna sought financial support from Work and Income New Zealand (WINZ) and/or Disability Support Link (DSL), which for both families was a challenging and disappointing experience. WINZ systems were seen as difficult to navigate and convoluted.

> The system is like completely like backwards, and it's so hard to navigate. Like you have to go to get the nanny, you have to go through WINS before you can go to DSL, but you have to go through WINS for WINS to tell you that you have to go to DSL before you go back to WINS for them to say, okay, you went to DSL, so now we can approve the nanny. And that takes like six weeks, eight weeks to do. And meanwhile you're at home with a newborn baby, unable to move. So, the systems are just bonkers (Anna).

Living off WINZ for Freya and her family was not really enough to live on.

> [My husband] had to give up work as well to become the carer for me and the kids...him giving up his job was the only way we could financially balance everything out and still have a functional household…we went from a two-decent income household to living off WINZ, which is not enough to survive, not when you have five kids...I'm sure there are things out there that would help more, but financially we don't have access to them (Freya).

Freya's comment about extra resources out there but not having access to them was in relation to the lack of recognition of long COVID as a legitimately disabling condition. This was seen as a major barrier for receiving financial and social supports.

> We fall through the disability cracks. It's not an accident, so you don't get ACC, it's not a disability, according to the, like, funding people, so you don't get any support for things like a shower chair, like a cane...I literally can't leave the house without either a physical support person or a wheelchair, but I don't get funding or support

> for those things, because it's not a disability, it's a medical condition, but you don't get any help for the medical condition, because there's nothing the medical field can do for you. So, because it doesn't have a medicine or treatment...you kind of fall through the gaps with all of them (Freya).

Chloe was the only participant who mentioned receiving financial supports via her workplace, which was "game changing" in reducing her financial stress while being unable to work and validating the legitimacy of her illness. Unfortunately, she was the only participant whose workplace had this income protection scheme in place.

> I think at this point I was off work again…so they were paying me, I think it was 80% of my salary and that took a lot of financial pressure off… so having this income protection insurance was also game changing…I was able to just be completely off work, I was like validated by the health system and insurance company, like "yes you are sick, this is a thing, like we believe you and its serious and we support you to not work" (Chloe).

4.2.2 Active Social Lives are Made "Small"

All participants experienced a shrinkage of their social lives due to the barriers imposed by becoming sick which restricted their ability to maintain connections outside of the home. The impacts of this lifestyle shrinkage were all encompassing. Emma's quote sums up the reality for all the participants: *"It's impacted almost every part of my life like quite severely... it made my life very small."*

For all the participants, leaving the house at times was very difficult due to physical symptoms, particularly fatigue, pain and brain fog. Freya drew upon the imagery of a reclusive hermit crab to explain her experience of social isolation:

> I don't have the energy to do that, so the kids interact with society less than they used to because I can't get out and about…so, I have found that the whole house has kind of hermited itself to accommodate me. (Freya)

Jane discussed how it was not just the fatigue that made socialisation difficult, but brain fog and Emma discussed how bright light outside the house was difficult.

> Some days like even just getting out of bed felt impossible. I'd try and like catch up with friends and stuff if I could, but I felt like…kind of feel like I'm not there, like I'm trying to have a conversation but like, I'm not there, it's like I'm in this hazy dream, like my brain's just not (Jane).

> I feel like our lives have become a lot smaller, because even things like going outside for a picnic can be really hard with the light, so just those daily like little small things that you do normally to make life kind of fun and exciting…I don't do those like I used to and that's a shame because…everyone wants their kid to have like some sort of magical childhood…not just a mum who can't leave the house (Emma).

The physical restrictions imposed by their illness left many participants upset about their abilities to create exciting lives for their children.

Long COVID symptoms also meant that hobbies and social activities that used to bring participants excitement, was no longer accessible to them. This impacted on mental health for many of the participants. *"Just going through that time of loneliness and isolation, because I didn't get a lot of visitors, it was me and my four walls*" (Anna).

> I got quite depressed, but it was simply from the lack of social, because people wouldn't come to me on my level to talk. We were the kind of house where we'd have barbecue on a Friday and everybody would come over...that was how life always was, and now there are two people that I communicate with outside of my husband, and that's, that's a big shocker (Freya).

It was not just long COVID's physical restrictions that became a barrier to maintaining active and social lives, but also social conflict with friends and family who did not understand or were heavily critical of long COVID.

> It literally got to the point where if that's your viewpoint, I don't have the energy to communicate with you anymore… they spend the whole visit trying to justify or tell me what I should be doing instead..."you just need this vitamin C pill, or my mother's best friend got Covid and she was fine, you're fine too", and I just don't have the energy for people like that (Freya).

> I know if I did make it out of the house, it's not socially acceptable to lie down when everyone else is sitting up chatting, or to only turn up for 20 minutes, or to even ditch big events like Christmas altogether. But I had to get to a point of, I can worry about the world's opinions, or I can just get on with surviving…and actually interact with people who got it (Anna).

Almost all of the participants highlighted encounters with controversy and people who didn't believe long COVID existed. Emma says, *"it gets a really negative response, and I think a lot of people still don't believe in it, you know, because they haven't personally experienced anything."* Similarly, Chloe recounted an experience where she *"had this physio recently where she seemed to not believe in long COVID, I just felt so angry."*

For Anna it hurt encountering people who did not believe that long COVID existed, and this was especially the case considering the impact long COVID had on her family.

> It was so hard as a mum and what my kids went through because of it, then anytime you get like disbelievers or people that think you're faking it...I don't have a word for that either, it's, it makes me angry. I think my kids went through too much to be part of an accusation like that (Anna).

Negative responses came from family and friends who could not accept the legitimacy of long COVID as a debilitating condition. In this way, people who had not experienced the impacts of long COVID were ignorant of its existence. Negative reactions were significant enough that most participants revealed that they dislike and/or avoid disclosing their long COVID diagnoses.

> I don't know if it's because people got tired of Covid so they've attached, like, it has the word Covid, you know, and they all got, I don't know, tired and angry over the lockdowns and stuff so anything that has the word Covid in it, is just like, "get rid of it all" or if it's just because they can't, like, see it, that they don't have a test for it (Freya).

Introducing long COVID into a conversation triggered the unwanted opinions and controversial views of others. It was the uncertainty over how people would receive their diagnoses that left participants hesitant to share their struggles.

> Everyone's caught in this weird controversy around Covid and it's, um, it's really detrimental to people who are suffering…I often don't even mention long COVID to people, I often mention my chronic migraines because I don't want to get into some sort of conversation about Covid is just like the flu, Covid is just like you know, it's because I had a vaccine…people just love giving their reckons on long COVID and Covid in general and I, I'm like I don't care about your opinion (Emma).

Even though social controversy also exists for chronic fatigue syndrome (CFS), Chloe still preferred to use this diagnosis over that of long COVID. This may speak to the reduced controversy Chloe experiences from associating herself with CFS instead of long COVID. She explains: *"I often tell people I have chronic fatigue instead because that's kind of a longer standing illness that people sort of understand, but then there are people in the medical profession who don't think that's a thing either."*

Hiding a long COVID diagnosis is a strategy most mothers used in social conversations with friends and/or acquaintances. *"I know a few people who have kind of come out with it, but they don't talk about it either…I mean, I'd love to hear more stories, but I don't think people feel comfortable talking about it"* (Emma).

For many participants, encountering people critical of their illness was an extremely hurtful experience which contributed to the shrinkage of social lives.

> I don't like telling people I have long COVID because you never know what response you're going to get, whether just ignorant or a conspiracy theorist or a genuine caring response ... so nowadays I keep my struggles with long COVID much more to myself and only really talk about it with new people I meet if I know they are a safe person. Because although I try to not let the sting of just how devalued your existence becomes in one single sentence, it still happens (Anna).

4.2.3 Missing Out on Motherhood: Long COVID "Kind of Stole It"

While all the participants found their lives made smaller, it was the impact on their families that many of the participants worried about. These restrictions imposed on the body by long COVID resulted in a sense of missing out on motherhood.

> I envisioned that life for myself and was so excited for [having a new baby] and obviously none of that happened, um, so long COVID it didn't shape it**,** it kind of stole it... as a mum, you always want to be accessible to your kids...but they weren't allowed that for a long time, it's sad (Anna).

> That was really hard because I just couldn't really show up for him, yeah, I could do the quiet parenting stuff like reading books or cuddle on the couch or watch a movie or something, but fun parenting stuff I wasn't really able to do (Emma).

The inaccessibility of social activities outside of the home had a negative impact on participant's abilities to be "fun and exciting" mothers. This led to guilt, worry, and sadness.

> I feel sad about not being able to do things…once I know I have to start taking medications…I've got to go home, like you know, I've got to stop whatever activity has been planned or anything that's in my imagination. You know, I know I won't be a fun mum…and so that it feels sad…it's still a bummer, it never stops (Emma).

> It was really heartbreaking not being able to do the fun things, and missing out on them…because you never get that moment back... so, it was heartbreaking...even just the normal day to day things, like just going down to the playground... I think those are probably the more harder parts of long COVID, yeah, just not getting to…make those memories (Anna).

The shift of being a mother prior to long COVID and now was mentioned by all the participants as devastating, which led to grief and a sense of missing out.

> The most devastating thing about getting sick…is that you immediately start to lose out on some of their childhood and you're no longer the mother that you want to be…I wasn't able to be playful to be just as engaged in his life, all of a sudden you know, I had to be physically removed a lot because…I thought I needed to just be lying down, resting all of the time basically and…that sort of fear that he would further fatigue me…I just didn't feel like I was the happy, engaged, playful mum that I had hoped I would be (Chloe).

Chloe mentioned fear – fear that her child could lead to a flare up of symptoms. While mothering can be very tiring in general, this sense of fear and worry that loved ones could be the reason for worsening symptoms, was striking. Chloe also discussed guilt as having a huge impact on her wellbeing.

> I think the biggest thing is like just the guilt, like just the biggest impact of like when you think about long COVID and motherhood…what you miss out on basically feeling like you've lost a couple of years, like a year or a couple of years of time with your child where you weren't able to you know enjoy that young cute toddler-ness and you have a guilt, just all the guilt (Chloe).

All participants were forced to rely on their partners, older children and/or friends for support out of necessity. This added a lot of work onto their partner and led to a personal sense of weaknesses. Chloe says: *"I couldn't fulfil like the duties of my life, like just kind of basic stuff. I was really having to rely on my husband and other people, and just, yeah, I just felt like a weakling."*

> He's like physically the only parent now...and I can't do it, so we can't job-share the parenting the same way, so if he can't do it, it doesn't get done…the only reason, as a parent, the only reason I've survived this is because I have a husband to pick up the slack (Freya).

Some of the participants had friends who helped with the children.

> I had a good friend who would come over and help with my child and that was amazing because you know, I would just be lying in bed or lying on the couch like in a dark room, like unable to do anything and like incredible pain…and she'd come out and actually take him to the park or like you know, do something fun that I couldn't do... If I hadn't had my friend come in for that first sort of year, like there are certain days I wouldn't have even been able to feed him, you know, like it was it was bad. I couldn't you know, stand up some days and do you know cooking and things (Emma).

By having people in their lives who they could rely on, participants felt that support was an extension of their own abilities. Anna describes this experience: *"requests that I*

make in a place of not being able to do them myself, when it's just a request and it's responded to then it's kind of like they become my arms."

Long COVID imposed changes on all aspects of the participants' lives from their work, their social lives and their lives as mothers. The changes all reflected restriction, smaller worlds and at times complete changes to the way life functioned prior to long COVID. This led to feelings of depression, grief, guilt and sadness. There were also feelings of gratitude for support, understanding and at times small wins such as stopping work which allowed for more time to be a mum.

4.3 Theme Three: Mothering Requires an Adapted Approach

This theme speaks to the specific intersections between the participant's long COVID and mothering practice. All participants felt that long COVID required a new approach to mothering which was necessitated by the limitations imposed on them by their symptoms. Due to symptom diversity, mothering was adapted in various ways.

4.3.1 The Physical Necessity for a New Approach to Mothering

Long COVID symptoms forced every participant to adapt their original approaches to parenting their children. Mothering with long COVID required adapting to new physical limitations which contrasted with pre-long COVID parenting. The overwhelming changes necessitated by long COVID mothering are described by Freya:

> It's just too hard, I can't, I don't have the physical ability to do that for this one. So, we've had to change the way we do things...that has come down to everything about the way I parent now…. now I've had to go, okay, let's take all of that learning we did [about how to parent] and throw it out the window, have to start again, because I caught a flu….I wasn't the sit in the corner and yell at the kids...I'm now one of those parents that sit in the corner and yell at you. I can't physically get up and come over to you anymore (Freya).

The participants utilised various new approaches within their new mothering practice; Freya introduced baby monitors and Jane introduced lay-down play time.

> We now have baby monitors in every room in the house, so I can just look at the monitor and check on the kids...because I can't expend the energy to get up and go,

> just to look in... whereas that's what I used to do...that costs too much energy now. So, we've had to find different ways (Freya).

> Sometimes I feel like I get really dizzy, like I feel like I'm going to faint and like in that situation I don't feel like it's safe for me to be carrying him…if the muscle aches are particularly bad or if he's like in a particularly wiggly mood… then I'll just try and redirect… maybe I'll like lie on the ground and he can climb over me…trying to come up with a solution that meets his needs in a safe frame (Jane).

These examples highlight how mothers adapted their usual approaches to parenting within the new bounds of their energy limitations.

Many participants avoided long COVID online support spaces due to negative experiences, however Anna found them a validating place to seek community and discover new parenting ideas with other long COVID mums: *"my online friends in the Facebook page got it...we swap ideas about how to mother when you're in a crash, or what activities to do for a now one year old when you're needing to be lying down."*

For Freya, adapting her approach to parenting was necessary to prevent over-exerting herself and entering an energy crash.

> ...you've made a mess on the floor, you need to clean it up, I get up, I come over to you, I sit down with you, we clean it up. That's not an option anymore because doing that will mean I end up sleeping for the next four hours...I've had to change the way I think about parenting because I can't physically do that stuff anymore (Freya).

Mothers wanted to be the best they could be for their children, even though this was at odds with their physical restrictions. For Anna, still being involved in the children's day was important to still feel like mum, despite her need for a nanny.

> I could do little bits because I needed to. I used to sit at the table in the morning and ask for bits and pieces to put in their lunchboxes. Silly because, I mean, the nanny can put things in the lunchbox, but I wanted to do it. I wanted to put their things in the lunchbox, so I felt like I made them lunch (Anna).

Despite adapting her parenting approaches within her new capabilities, not all parenting dilemmas could be adapted to; long COVID was still a restricting factor for

their families. For Anna, it was a heartbreaking experience when her children could sense her usual ways of being mum were impeded by her illness:

> I actually made it to her first day of school because I was adamant I was, [but] then have that being it, like having to not be part of dropping her off at school every day and not picking her up. And she used to say to me, "why, why did [my older brother] get, why did you walk him to...his classroom, but you don't do that with me. Why do I have to catch the bus home?" stuff like that, yeah, it's heartbreaking (Anna).

For Emma, her mental frustrations of living in a painful sick body require her to place restrictions on her son's activities when they are at home, more so than before becoming sick.

> Emotionally I'm probably more likely to…have a shorter fuse or something like that if I'm in pain that day…there's probably more restrictions on what [my son] can and can't do. Like…if I'm not feeling well, like lights and noises and things like, you know, I'm like "oh can [you] not do that?" you know, "please like it's too much" (Emma).

For one participant, Chloe, increased health knowledge fuelled her desire to change her parenting approach to become a calmer mum for her son:

> The role of the nervous system has really informed a lot of my parenting and the way that my parenting has changed because I'm now trying to be a much calmer parent for my health, but also for my son…we now have different approaches to parenting…because of my health journey and the things that I've learned, the tools that I now have…I also look out for his nervous system a lot more (Chloe).

4.3.2 Long COVID Mothering Conflicts With Good Mothering

Most participants understood new ways of mothering to be examples of "bad parenting". This was discussed in relation to the societal pressures on mothers to fit within the cultural stereotype of good mothering. Being forced by their symptoms to resort to "bad parenting" some participants were left viewing themselves as "failures" and having "lowered their standards". In this way, mothers understood their adapted mothering approaches as less than ideal, which heightened feelings of guilt.

> You have to survive really, that's the crux of it, I don't get the luxury of choice sometimes and I didn't when I was bed bound. Those choices are for people that can afford to be socially acceptable, that aren't in the position to have to choose bed for a week or an extra three hours of screentime. So, there was tremendous guilt and kind of hiding as much as I could from the world to keep away from that judgement from people because it's not acceptable. Neither is it normal to barricade your baby and only let him live in the lounge, but I had to do that cause if he crawled out of the lounge, I couldn't go after him (Anna).

Participants discussed various examples of long COVID mothering which required "bad parenting" approaches. Anna discusses co-sleeping with her baby:

> A big one in mothering...was co-sleeping. That is a huge thing in early baby's life that is so educated, talked about and known to be a big no no. But even the health professionals and midwives in our care had to concede that it's what I had to do and worked with me to do it safely as possible, but when people find out about it, you're criticised and given all the tips on how to get baby in bed as if they know what it's like to have fatigue (Anna).

For some mothers their reliance on screentime to entertain their children was a source of guilt considering a social narrative that "screens are bad."

> Also, with the perception around being a mother...often it would be definitely around the use of screens and how much screen time we've had to have in the last couple of years. I think that was a really hard thing to accept because you're sort of told that screens are bad, but luckily that happens inside the house, so people don't see that...you still feel bad about it. A lot of mothering I think is all inflicted on yourself, like you are worried about how I'm doing as a mother, even if no one can see how it's going, I still feel like I'm failing (Chloe).

For Chloe, she was glad she could hide her reliance on screentime within the house, however, for both Chloe and Anna they were still plagued with mothering guilt.

Many mothers expressed worries over how society would perceive them as "bad parents" by the choices they were forced to make due to their long COVID. Two mothers

discussed this well in the context of visiting public spaces; for Freya this was the supermarket, and for Chloe this was the local park.

> I know if we were to do stuff like that [visit the supermarket], that would be frowned upon. You'd be a bad parent because you aren't teaching her to behave…I know her behaviour is very different, and society would perceive it as bad parenting (Freya).

> In the playground...I would be sitting on a bench not physically engaging with my kid and that would feel, there was a lot of feeling like yeah, I wasn't doing a good job. People would see that I wasn't, you know, over there doing that. I would just look lazy and disengaged (Chloe).

Pressures to parent in an appropriate way not only came from wider society but also within the relationship with their partners. Chloe would solo-parent her son for half and week and co-parent with her husband for the rest. She highlights her differing experience between the two:

> You feel less judgement when there's no one else in the house to judge you, so I was able to really lower my parenting standards for myself when I was solo parenting...you can really just let that go just in survival mode (Chloe).

Chloe understood her adapted approach to mothering to be a consequence of lowering her parenting standards, thus viewing long COVID mothering as less desirable and socially acceptable than pre-long COVID parenting.

To combat feeling pressured by others to conform to the good mothering stereotype, both Freya and Anna expressed ways that they distanced themselves from social parenting standards.

Freya approached this by a process of accepting her new limitations and re-framing her understanding of what good parenting looks like now within her "new body."

> I actually had to change or let go of my beliefs around parenting and what was good parenting. I either had to accept that I had become a bad parent, or I had to change my beliefs around what good parenting was. Because now, good parenting is you're alive and happy, and that's it… whereas before, it was about having good manners and morals, and you know, I had so many more rules. So, I had to let go of a lot of

> that, and that was quite an adjustment…I had to find a way to see myself as a good parent in this new body. Yeah, because I couldn't accept being a bad parent. That was too hard (Freya).

Anna approached this by distancing herself from the pressures of good mothering by redirecting her mental focus on what was important to her; herself and her family.

> There's what's normal and what's socially acceptable…and then there's living with a chronic illness and allowing yourself to not judge yourself like others do in all the ways you have to find to mama….I had to get to a place of where my responses didn't let me care about what my social norms looked like to anyone else, except my fatigue levels and the hopes to not being a crash tomorrow, my home, my kids, my health, my responsibility to get through it, not society's. Society doesn't live with long COVID, I do (Anna).

For these mothers, an adapted approach to mothering was forced out of necessity due to the limitations imposed by their symptoms. Mothers approached new parenting techniques in various ways; however, this often came at a cost to their abilities to conform with socially acceptable mothering standards. Together with their self-imposed labels, mothers were left filled with guilt and worry. Some mothers addressed these standards by re-framing their own beliefs around what mothering with long COVID had become.

4.4 Theme Four: Mothers Experience Pressure to "Push Through" Symptoms

This theme introduces how all participants experienced pressure to "push through" their long COVID symptoms. Despite medical advice to rest, caregiving responsibilities remained and mothers felt they needed to push past their symptoms for the sake of their children. Pressures to "push through" their discomfort was understood by many mothers to be linked with the stereotypical expectations for mothers to always be self-sacrificial.

4.4.1 The Necessity to "Push Through" Symptoms

Mothers understood that "pushing through" their long COVID symptoms was a necessary feature of having both parental and work responsibilities that demanded energy alongside caregiving. Mothers viewed themselves as having no other option.

> I never would have thought before having my son that I would have been able to like push through to the extent that I am, but you kind of just do because you have to…so it's like this weird primal thing that just takes over (Jane).

Part of "pushing through" symptoms required supressing the demands of their own bodies from fatigue and pain to prioritise the needs of their children first.

> You're already fatigued at the beginning of the day, but as you start the day as you're using your energy, it gets less and less and less. So, the fatigue gets higher and higher, but you still got to look after the kids, you still got to do the school run, or take them to swimming, so, you just push through it until you just absolutely can't anymore (Anna).

> Probably the biggest thing as well is that you go out in the world because you have to...I still had a child...if you had a tiny amount of energy for that day you would rally it for this one outing so that you could drop your child off at school or go to that family dinner or whatever (Chloe).

Despite being aware of the negative consequences that pushing through their symptoms would have for their own wellbeing, mothers still understood it to be necessary. Jane says: *"I think just by the nature of constantly putting someone else's needs before your own, like it just means that you are not meeting your own needs."* This was echoed similarly by Emma: "*Pushing through is quite a bad thing to do for your mental health or for your physical health but you know it ends up being necessary*."

As a mostly solo-mum, Emma's experience of "pushing through" her symptoms also related to her reliance on retaining her job. The fact she was able to push herself through work, meant she could maintain financial security.

> I was able to hang in there and keep these jobs…if circumstances have been slightly different for me, you know we might have been worried about our home situation or

> even having a place or I might not have been able to do absolutely anything, there'll be no support (Emma).

However, the consequences of pushing through at work depleted her already diminished energy availability that could otherwise be used with her son.

> You end up using all your good days on that [work] and then you just shattered in the weekend, and you can't like, interact with your child properly, you've got like nothing left physically…so that sucks too (Emma).

4.4.2 Fatigue and Self-Sacrifice are Normal: "You're Just a Tired Mum"

Some participants felt pressure to push past their symptoms because of a social norm that fatigue was an expected element of motherhood. Anna says: "*just trying to tune out the criticism from people that think you're just a tired mum and you should do what all mums do and get on with it*."

Labels of being "just a tired mum" delegitimised the participants experiences of fatigue as a valid struggle. Instead, the inherent tiredness that comes with motherhood was used as an explanation for their struggles. Instead of having their fatigue acknowledged as a legitimate symptom of long COVID, participants were gaslit, both medically and socially, into thinking that their fatigue was normal. For Anna, the judgements from other people left her emotionally wounded.

> It makes the illness seem like it's not there at all and what I'm going through is normal and I just need to get on with it and stop complaining, stop laying about, stop whatever it is people imply I need to stop... I was dismissed because no one valued how bad it was for me and passed it off as pregnancy, then when he was born, being a new mum and I do carry wounds from when I let those comments become me (Anna).

A consequence of having their fatigue labelled as normal motherhood, many participants were left questioning if their fatigue really was normal motherhood or long COVID. Chloe sums up the mental dilemma: "*There's another thing now, about coming out of the hardest parts of the fatigue and trying to work out what's normal exhausted motherhood and what's chronic illness*." In this way, the social expectation for

motherhood to be tiring creates a climate whereby participants felt pressured to push through their long COVID symptoms.

Mothering was also understood as an inherently self-sacrificial social role. Almost all participants embodied this aspect of motherhood and therefore felt it necessary to "push through" their symptoms for the sake of their children.

> I think my kids have always been my world and to see them hurting and not being able to see me or, um, yeah, I don't know, like every little but of energy that I had, I gave to them, yeah, they need it (Anna).

> He wants to be carried around a lot and that's painful for me to do it, but I still do it because that's what he wants and needs in that moment…it's kind of just being a mum…so it means it's my job to look after him and put his needs first… I think in general…just push through like…I never realised before becoming a mum like how far I could push myself (Jane).

The self-sacrificial element of mothering was understood to be even more costly within the context of long COVID where there was less of yourself to give.

> It's really hard because I guess as a mum, most of your world, when you don't have long COVID is geared towards your kids and making sure they are safe and happy, and you sacrifice a lot of yourself for them. But then with long COVID, it's like, you don't even get that little bit to set aside for yourself...most of what I want as a person has to take a step back (Anna).

Despite the negative consequences of "pushing through" and surrendering their own needs, participants wanted to be there for their children.

> Pushing through makes it seem like it's a really negative thing, but I don't, it's not necessarily a negative thing…like I want to show up for my son, and like yes it's hard to push through…but like I love him, I love spending time with him and that would always be my choice I think (Jane).

Chloe and Jane highlighted that their ability to "push through" their symptoms was fuelled by the joy of playing with their children. The joy they received seeing their children having fun improved their own sense of emotional wellbeing.

> I sort of learned through the process, you know, that engaging and joy would help…and the idea that maybe it would be physically taxing to kind of go and play for a bit, but it came with a benefit…that would then actually contribute to healing in a different way. So, while physically tired, I was then like emotionally buoyed in a way that was positive, but it took me a long time to work out that that was a good thing (Chloe).

> On the weekend, you know, I'm exhausted, I don't want to go out, but we go out and he's like having the best time at the park, and you're like yeah this is good, you know you get energy then cause he's having fun, so you're like, oh we'll run around and have more fun together (Jane).

The main medical advice given to the participants was to rest. However, physically separating themselves from their children came with feelings of guilt and failure. "Pushing through" their symptoms instead of resting helped them to feel like better mothers, despite neglecting their own physical needs.

> I'm afraid of energy expenditure and often don't do things as I tell myself I'm tired and can't afford it… so I thought I was doing the right thing by lying down and resting and healing… I've been trying lately to choose to do more with [my son], play more, or be more playful and even when I feel tired and I think the payoff is worth it. I feel joy and I feel relieved of some of the guilt that I carry and that I can't be enough (Chloe).

Jane refers to how her experiences with Kiwi (New Zealand) culture intersect with the pressures to ignore how sick she really felt. This likely reflects the powerful impacts that cultural expectations to "push through" have on how Jane experiences her illness. The discordancy between culture and reality left Jane feeling like she "was failing" and therefore, her difficulties coping with illness were a personal fault. Jane says:

> It's like a Kiwi culture thing… just get on with it, like just push through, it's fine just keep going…and so it was like a sense of failure or like sense when I was being like lazy or something like that…getting to the point where I was like, I can't just get on with it, that really felt like I was failing. So, I think then having that experience being referred to as like being tired or something like that really reinforces that sense of

failure for me, because I'm like oh I'm just tired, I should just keep pushing through (Jane).

4.4.3 The Consequences of "Pushing Through": Energy Crashes and Burn Out

All participants experienced consequences of pushing past their symptoms, which was primarily an energy crash (i.e. Post-Exertional Malaise). In a similar way that long COVID symptoms and their intensities were so varied, so was the embodied experiences of an energy crash. Navigating the risk of entering an energy crash was a challenge for busy mums, especially when bodies did not respond in ways they used to. *"How much can I do before I'm burnt out? What are the signs, how do I recognise? It's like learning a whole new body because it doesn't respond the way it used to*" (Freya).

> Every now and again, this is again a bad thing probably, cause I'll push, push, push, and every now and again maybe once every month, once every couple of months, I just like hit this wall like hard and I just like I can't push through anymore…I just have to lie down in bed for like half a day or something, cause like I just can't anymore (Jane).

For Chloe, pushing through her symptoms was a way to "mask" the illness from other people. However, the process of masking would deplete her energy and place her at risk of a crash.

> Masking symptoms to try and be in the world, pretending you're fine so your kid isn't affected by sick mum, but this equals overdoing it and eventually snapping or having to crash worse later…for an hour I could sort of pull it together and have people over for a meal...so they would leave and then I would go to bed, and my husband would deal with the rest...and I would probably also then yell at everyone for the rest of the day because I was exhausted and overstimulated and all that stuff (Chloe).

The intensities of energy crashes varied across participants, but they all often relied on the support from others to help them through. Anna and Freya's energy crashes were intense experiences. Anna recounts: *"during the bed bound days...I would be like completely paralyzed... like if my head fell to the side, I couldn't pick it up, like*

somebody would have to physically pick it up for me." Freya shares a similar reliance on others for support during an energy crash: *"there were patches where, because I was trying to live my old life, I'd burn myself out so badly that [my husband] literally have to come and walk me to the bathroom, or I wouldn't go."*

For the participants, their perceived roles as mothers necessitated that they "push through" their illness symptoms for the sake of their mothering responsibilities. The pressures to keep going despite illness existed within a social climate where fatigue and self-sacrifice were expected elements of their mothering role. However, this came at the personal cost of an energy crash, where participants were often reliant on the support from loved ones to get through. Despite the personal costs of ignoring their symptoms, many mothers felt joy by being present with their children, which alleviated guilt that came from when they eventually needed to rest.

4.5 Theme Five: Changing Identity and Self-Reflection

This theme introduces the widespread effects of long COVID on the participant's sense of self. The recognition of having an altered sense of self was an emotional experience for many participants, which for some became a grieving process. Additionally for some participants, living with long COVID encouraged a period of self-reflection whereby life priorities were reconsidered in light of living with a newfound chronic illness.

4.5.1 "Lost Who I Was": An Altered Sense of Self

All participants understood that their experiences with long COVID had changed their sense of self. For some participants, a changing sense of self was characterised by loss and grief. This quote from Anna summarises this element: "*I feel like all of me was gone, really, like every aspect of me, I was just there watching...it's really soul destroying."*

Changes to their sense of self manifested in various ways for each participant, but the effect of a changing identity was all encompassing. Emma says: "*I didn't think it would change my life so much, yeah, but it has…I'm a different mother, I'm a different person, I'm different to my friends*."

Many participants found their altered sense of self was an unexpected consequence of becoming sick. This quote from Freya demonstrates this surprise:

> A physical medical condition doesn't change who you are as a person, but it actually does, this this one does, I never would never have considered how much of a personality change I would have to go through because I caught a virus (Freya).

For some participants their loss of identity was primarily around losing their sense of self as active people and parents. This changing sense of self was echoed by sentiments of loss, denial and mental adjustment.

> I was like in denial and I only just sort of came to terms with that in this last week that it's, it's a major personality shift, it's like, I can't do all these things you've loved and cherished and you know, all of a sudden you're like some sort of invalid or something and its awful… from being like vibrant and doing stuff to take my kid… to being someone who like is basically a mole who lives in, like a little mole house with all the lights off, like it's, it's awful (Emma).

> The harder part was actually mentally adjusting to the fact that I wasn't who used to be anymore...I was a go-person. I was an active parent...but that person is not this person and that is probably actually far harder than the physical adjustment to realise that it has actually changed who I am. I can't be the active parent that I wanted to be, so I've had to learn an entirely different way to parent...I felt like I lost who I was, and that was really hard (Freya).

There was a sense of long COVID having forced a change in how the participants viewed themselves, particularly their ability to parent like they had before.

For these participants, the physical restrictions of living in a sick body left them feeling like the shell of a person. This lack of autonomy and reduced ability to care for themselves and their families was a challenging and emotional experience. Physical and mental capabilities had been stripped from their bodies and so had their previous sense of self. Anna emphasises how her loss of self was tied to her new physical restrictions:

> I kind of felt like I was nothing because I did nothing. I had other people looking after my children and I didn't have ability to do anything for myself, like your hobbies and your passions and my role as mum was gone and I really felt like I was just

> something to be fed and washed and put to bed, that's where I spent my whole day (Anna).

Physical limitations not only impacted the participant's sense of self as mothers, but also within their professional lives. Jane demonstrates this element:

> I didn't actually realise this until I stopped working because of long COVID. I place a lot of value in who I was as a person based on my work, essentially, and being a good worker and being a hard worker, so leaving work was a big deal for me and I didn't realise until after I'd left and I was like, I just feel like useless (Jane).

For some participants, their loss of identity as "vibrant" and "active" people meant that they considered having long COVID as disabling despite others not recognising their new disability. Freya says: "*it's so complex, and it is on so many levels...it's getting used to physically doing different things. It's getting used to being disabled but not being perceived as disabled*."

Some mothers associated their changing sense of self with negative self-judgement. Emma shared that although she could still provide emotional support for her son, having lost the ability to be physically active meant she viewed herself as "a terrible parent." This change was a mental challenge:

> I would come home and I was just like, unable to move, basically, such a terrible parent, unable to do fun things on the weekend…I am a caring mum…I'm like always there for him, like emotionally, you know, but I'm not the fun mum that I thought I would be you know, and it's like important…. I think you beat yourself up a bit as a parent anyway, wanting to be a good parent and so when you can't like physically show up for your child, it's definitely hard (Emma).

Some participants viewed their new physical restrictions as having rendered them "weak" and "useless". For Chloe, long COVID altered her sense of identity to become someone who was broken and damaged. Through the use of a metaphor, she attributes her loss of health to be a personal moral failing:

> So you know how in Jane Austen there's always like a character who gets headaches or has like this sort of weak disposition where she's always having to lie down in the

> dark room, and that character is never one that you like...they're never a good character, it's like a negative trait for this person to have this kind of weak disposition and I felt like that character, I felt like this unseen illness that's just kind of, I'm just a bit useless...I remember feeling like I had let [my husband] down and let [my family] down in terms of like**,** I was like a lame horse...suddenly I wasn't the like fit healthy young person he had married, I'd become this like useless lame character from a... Jane Austen book (Chloe).

Chloe's identity shift is one characterised by personal blame and having let other people in her life down by viewing her fatigue as a "negative trait". Similarly, Emma's sense of positive self-identity dwindled as a consequence of the physical restrictions of long COVID: "*I still feel like quite boring…it might be that I've just been like this for so long that I just end up being a slug."* Not only do these participants see themselves as changed, but that these changes constitute a "negative trait", as evidenced by the imagery of a slow lethargic slug. The new self-labels participants gave themselves were primarily negative, echoing a sentiment of loss and failure.

For many of the participants, experiencing a loss of self was understood as a process of grief and acceptance. Freya describes her experience with grief:

> That was the hardest thing I've ever been through, because you go into, almost like a grieving process, like I lost a whole person, I lost my person...it's kind of confusing because you're grieving, but you're grieving for yourself, but you're still here...it was definitely like, I don't know, soul-destroying...it's the worst thing I've been through, for sure. In terms of just accepting that I cannot be the person I was, accepting that the person is gone and they're not coming back (Freya).

Anna was the only participant who used the help of a home nanny to care for her newborn baby while she was bedbound. With the arrival of the nanny, Anna unexpectedly felt like she'd lost her sense of self as a mother:

> When she came, I was kind of expecting to still feel like mum, yeah, but I really didn't…it was somebody else in my home that I didn't know that didn't understand the importance of me getting to be mum, me getting to have a say in my own home

> with my own baby…instead, it was more like a nanny taking care of my baby while I sat there (Anna).

Reliance on the nanny's support reduced Anna's sense of autonomy and identity as a mother. This autonomy was immediately returned upon firing the nanny: "*When she left, I was like I get to be mum again, yeah, and that was worth it...I didn't need to battle with anything…. it just immediately gave me so much more in my heart*."

4.5.2 Self-Reflection and "Unexpected Positive Learning"

Some participants discovered personal and positive meaning from self-reflection on their journey living with long COVID. Through reflection, participants expressed finding unexpected value within their struggles.

> The positives that I've got out of it were unexpected…there have just been so many positives…tools that I will use for the rest of my life that have been really beneficial... I definitely think that there has been… some positive outcomes from this experience that I will hopefully use for the rest of my life, but I still don't know if it was worth getting sick (Chloe).

Living with long COVID was challenging, but participants who saw personal growth through adversity were able to reflect on this, as evidenced in this quote by Anna:

> I often say that long COVID is the best and worst thing that ever happened to me...I don't want to go through it again, I'm still going through it, but definitely that bed bound stage, it has produced a lot of growth in a very short time. I think anyone that goes through really hard times like that often does that (Anna).

Many self-reflections encompassed a newfound recognition of the importance of health, wellbeing and family. For Chloe this was a mental transition:

> There's nothing more important than your health and your family, there is just no doubt in my mind and it seemed to obvious, but I think until both of those things have been challenged, you don't really appreciate them and how simple the world is when it comes down to it…I feel healthier in a way in my body holistically, like all the things that I understand about how to live in a better way, I have all that stuff now that I didn't before…like a mental clarity (Chloe).

Similarly, Jane understood her long COVID journey to provide her with a newfound appreciation for health and family.

> I think it's like healthier, weirdly, like it's a healthier mindset to have to just kind of let it go a bit…there are many parts of my life that have changed significantly…what's super important to me is, is my family now, and so like that's kind of probably a big change, which I can easily tie to both parenthood and long COVID (Jane).

At the time of the interviews Anna had experienced the most improvement in her symptoms and also expressed the greatest sense of self-reflection and personal growth. This was particularly evident in this quote where she outlines her transformation from intense depression to the recognition of her inner strength:

> When I got back up on my feet, I've kind of been like, well, who am I in the world and where do I fit in and what do I mean to the people that love me?... I think that the long COVID journey is and has taught me a lot, and what I'm learning is that even though I was in a really, really dark place during the bed bound stage, and that takes you to places of not wanting to be alive anymore... I've discovered that I am actually really strong despite being in those dark places (Anna).

Few participants discussed the concept of recovery from long COVID which was not surprising considering the lack of medical knowledge in this area. However, Anna discussed the importance of generating hope amidst the medical uncertainty. She found this through the creation of a collage which became a vision board for the future. This hope was critical to her sense of wellbeing.

> What do I actually want to do in life? What do I want to do with my kids? That's when I started making a vision board of all the things that I missed out on…I think what helps me stay well and keep well and keep moving forward in the recovery process, because I think before when I was just bed bound and all the doctors said was "don't know"… that's all the messages I ever got. I never got anything hopeful. Yeah, the vision board is hope. You need that to keep going (Anna).

Living with the physical and mental restrictions of long COVID led to widespread changes in all participant's sense of self. An altered sense of self was primarily negative

and reflected the loss and grief of a former identity. Experiences of identity changes were unexpected to the participants, as was the positive life reflections that some participants also experienced. While not all participants recognised positive self-growth, those that did used their experiences with adversity to reprioritise what mattered the most to them in life, namely health and family.

CHAPTER FIVE: Discussion

This thesis explored the lived experiences of five mothers medically diagnosed with long COVID. Overall, the findings illustrated lifechanging impacts and challenges that were exacerbated as this is a particularly newfound chronic illness with debilitating and complex symptoms. The findings from this research produced five themes (*An Uncertain Illness with Invisible Symptoms; Symptoms Impose Lifestyle Restrictions; Mothering Requires an Adapted Approach; Mothers Experience Pressure to "Push Through" Symptoms;* and *Changing Identity and Self-Reflection*). The participants faced the inability and/or reduced capabilities for paid work, housework, and childcare. The physical and mental demands for rest meant that partners, friends and family were required to take on additional responsibilities. In particular, the invisible and often stigmatised experience of symptoms created barriers for fulfilling social lives, getting people to understand the seriousness of their condition, and made it difficult to access formal support. Motherhood added complexities to the participant's experiences of long COVID, whereby pre-COVID parenting approaches were adapted within the bounds of their new physical and cognitive capacities. However, adapted mothering was met with internalised and externalised conflict with good mothering ideologies, and many mothers felt guilt and shame from this tension. Falling ill with long COVID also altered the ways mothers viewed themselves, their families and, for some, sparked wider self-reflections on life in general.

This chapter discusses the findings of this thesis with support from existing literature. Firstly, the impacts of long COVID are outlined considering the biopsychosocial model. Then, the intersecting elements of long COVID in motherhood are considered within the theories of biographical disruption and social role conflict. Lastly, this chapter outlines long COVID as a legitimately disabling illness, with practical recommendations and the need for future research.

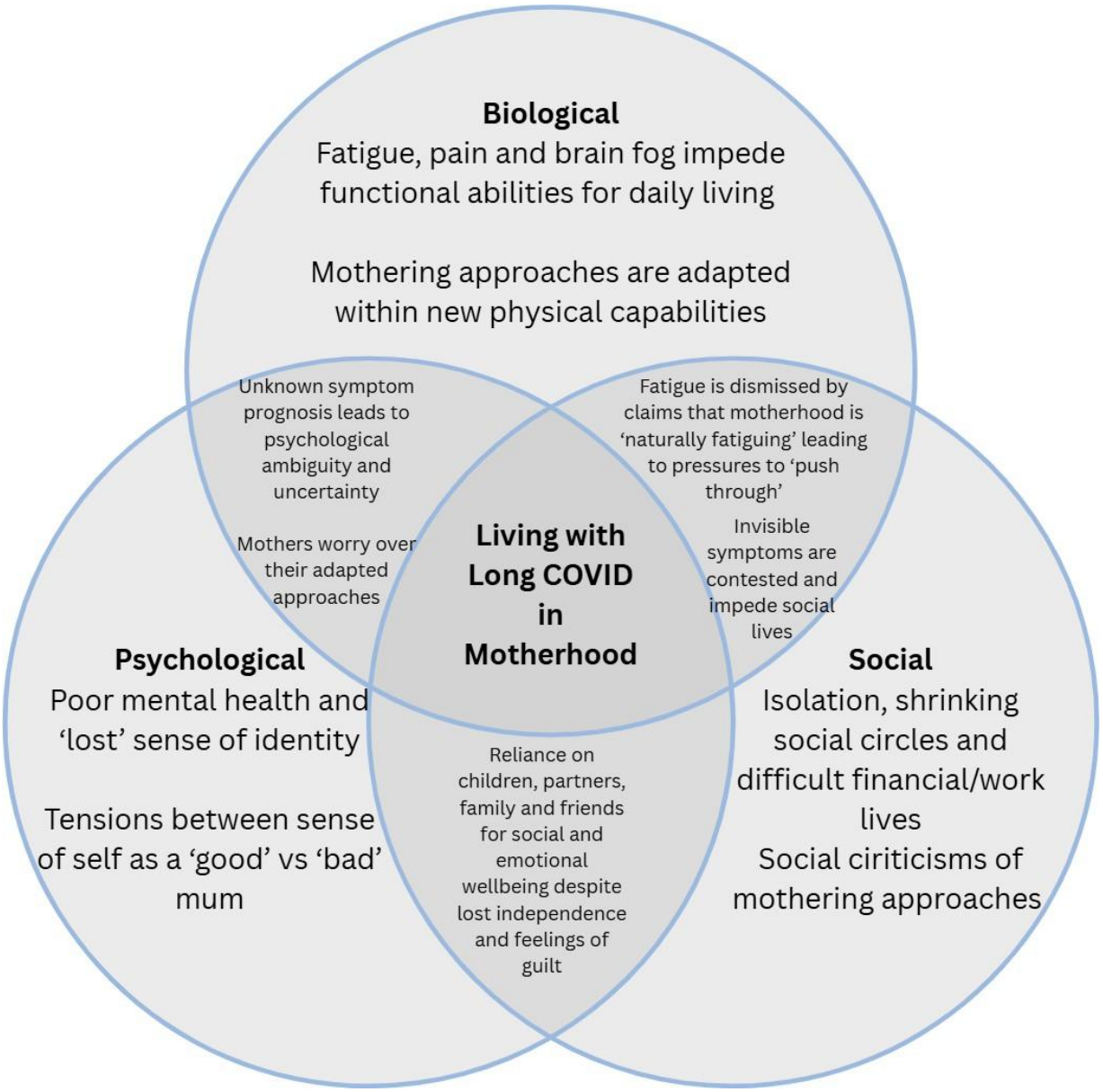
5.1 Long COVID and its Bio-Psycho-Social Impacts

The findings from this thesis support a dynamic biopsychosocial understanding of long COVID (Lehman et al., 2017). All participants experienced negative impacts from long COVID on multiple domains of health. These included physical,

psychological (emotional and sense of self), and social (work and recreational) elements. I have summarised these in Figure 1.

Figure 1

Biopsychosocial Features of Long COVID in Motherhood



Of particular note, these domains of health were not affected in isolation, rather a dynamic interaction between these domains resulted in the overall challenging and debilitative consequences of living with long COVID. This element of the findings supports a dynamic biopsychosocial lens when considering the impacts of long

COVID, and this is also supported by other literature that has called for the biopsychosocial model to be the "underlying philosophy of understanding" in long COVID (Thurner & Stengel, 2023, p. 599), along with others (Claessens et al., 2025; Klinkhammer et al., 2024; Sirotiak et al., 2026; Skilbeck et al., 2023).

There was no single narrative for the long COVID experience in motherhood. Instead, common domains of life and health were negatively impacted within the participant's diverse socio-economic contexts. Emphasis on the interactions between various biological, social, psychological elements is important for a holistic understanding of the illness grounded within each person's unique lifeworld (Lehman et al., 2017). It has been argued, and this thesis supports this, that attending to the interacting elements within a "broad perspective of patient suffering" is important for directing research beyond just biological targets, but also on psychological, social levels too (Thurner & Stengel, 2023, p. 559). Research by Wiertz et al. (2025) applied the concept of the biopsychosocial lens further to consider long COVID rehabilitation experiences and found positive impacts from this holistic approach. Furthermore, long COVID researchers call for holistic healthcare by incorporating the skills of allied health departments (i.e. occupational therapy, psychology, social work, dietetics, physiotherapy, and speech pathology) (Alexander et al., 2025). On a local level, the New Zealand guidelines for long COVID care emphasise the need for integration of physical and psychosocial support opportunities to contribute to rehabilitation (Ministry of Health, 2025). It is the diverse fluctuating nature of long COVID symptoms and their meaningful impacts on quality of life that necessitate the diversity of support from a range of health professionals (Broadley et al., 2025).

5.1.1 Biological: Symptoms and their Functional Impacts

The biological manifestation of long COVID had consequences for the participant's physical day-to-day functioning. Participant's symptoms were diverse which included pain, migraines, nausea, skin irritations, sensory sensitivities (light, sound etc.), fatigue and brain fog (poor concentration and memory). Not every participant experienced each of these symptoms, however both extreme fatigue and brain fog were primary symptoms for everyone. Difficulties performing daily tasks such as exercise, paid work, housework, childcare and preparing meals imposed significant

changes in the participant's lives. This meant that partners, family and friends were relied upon to 'fill in' where support was needed. Existing literature supports the debilitating impacts that long COVID has on functional abilities (Chasco et al., 2022; Humphreys et al., 2021; Ladds et al., 2020; Pearson et al., 2022; Wiertz et al., 2025; Wurz et al., 2022).

A specific feature of long COVID that was often mentioned by participants was difficulties with the invisibility of their symptoms. All participants struggled with a lack of objective signs and symptoms that they were unwell. Many participants struggled in social settings whereby others did not believe they were actually sick due to a lack of physical evidence. This is not uncommon in research on other contested illnesses (e.g. chronic fatigue) whereby the burden of proof is often placed on the individual to prove they are unwell enough, Dumit (2006) describes these as "illnesses you have to fight to get" (p. 577). Multiple sources of long COVID research discuss challenges that people have with their invisible symptoms (Bovo, 2021; Leggat et al., 2024). The lack of physical symptoms seemed to play out for mothers particularly considering a social narrative that motherhood is a naturally fatiguing experience. This created tensions for participants to have their experiences with extreme fatigue legitimised in social settings.

Considering long COVID's contested nature, it seems that the invisibility of symptoms plays a part in experiences of stigma and gaslighting. A study by Rhodes and Douglas (2025) found that the nature of long COVID's invisible symptoms contributed to experiences of medical gaslighting within New Zealand primary care settings. Specifically, people with long COVID recounted experiences with medical professionals who were dismissed and blamed for their illness (Rhodes & Douglas, 2025). The experiences recounted by Rhodes and Douglas (2025) closely resemble those within this thesis, which supports the phenomenon of medical gaslighting within Aotearoa New Zealand primary care settings. Experiences of medical gaslighting are also experienced within other contested and invisible illnesses such as endometriosis and pelvic pain, whereby people (often women) face difficulties in having their symptoms believed (Brauer et al., 2025).

Due to a lack of objective signs and symptoms, some participants often wished for more physical 'evidence' that they were unwell, often referring to broken bones, plaster casts, and the effects of chemotherapy on the body. Looking well on the outside contributed to a sense of social isolation and feelings of being misunderstood. Other long COVID research also highlights that people wish for more physical signs so others could see they were unwell (Rhodes & Douglas, 2025; Sirotiak et al., 2026). The barriers that invisible symptoms pose for feeling validated and believed are similar to many other illnesses with largely invisible symptoms. For example, research on people with fibromyalgia (a chronic condition of body pain and fatigue), which shares many symptoms with long COVID, has highlighted that people also wish for more visible symptoms to feel understood (Colombo et al., 2025). Another contested illness that shares similarities with long COVID is myalgic encephalomyelitis/chronic fatigue syndrome, and research has identified that people also struggle with the invisibility of their illness which pose barriers for participating in home and work lives (Khalafbeigi et al., 2023). Considering the emergent nature of long COVID, researchers have suggested utilising recovery frameworks based on similar conditions, such as these, where symptoms and their lived experiences cross over (Rhodes & Douglas, 2025).

Another overarching feature of long COVID for the participants was the medical uncertainty around diagnosis, treatments and if there is potential to make a full or partial recovery. This is partly due to the fact the medical profession is continuing to understand the physical causes, treatments, and outcomes for people with long COVID (Levin & Bradshaw, 2025; O'Brien et al., 2025). All the participants were medically diagnosed with long COVID, but all of them spent times stuck in diagnostic limbo for months or years as medical professionals ran through numerous tests to arrive at a diagnosis. The diagnostic uncertainty and lengthy wait times left participants physically and mentally struggling. Once a diagnosis was offered participants hoped to finally receive support, however many participants felt a sense of let-down when little support was offered and/or they were just told to rest. A participant remarked that this process was a "*whole world of unknowns*" that they needed to navigate. Delayed diagnoses are a common experience within contested illnesses (e.g. chronic fatigue) whereby

diagnoses are given based on patient accounts of subjective symptoms which can be treated with scepticism by practitioners (Dumit, 2006).

What this research has shown is that being a mother presenting with biological symptoms related to long COVID complicated the diagnosis process. Participants felt that medical professionals were still really unsure of trajectories or treatment, particularly for two women who were pregnant during long COVID. The increased fatigue of having multiple visits to health professionals as well as managing this with children was considered a huge barrier. They felt that they were dismissed in their struggles as motherhood was socially considered a naturally tiring and difficult experience, and this view seemed to contribute to delays. Finally, the impact of the invisible physical symptoms of extreme fatigue and brain fog were not fully considered medically or socially within all the domains that are impacted by mothering as outlined in matrescence (Athan, 2025; Slootjes & DeRolf, 2025).

5.1.2 Social: Support, Employment, Finances and Stigma

There were many challenges to consider with long COVID. One of the challenges was the nature of reduced physical functionality which limited the capacity for all participants to take part in social activities. Formerly active and exciting social lives were reduced to smaller social circles. The lack of physical and mental energy for socialisation (keeping up with conversations, remembering names/events, having physical energy to stand up and interact) became the main barriers for participants to maintain important social connections. Many participants felt socially isolated as a result of this. This is consistent with research by Hajek et al. (2025) that long COVID is significantly associated with women's sense of social isolation. Additionally, research by Rottstädt et al. (2025) has shown that people with long COVID gain less satisfaction from socialisation compared to those without this illness. The authors argued that fatigue was the main determinant of reduced socialisation (Rottstädt et al., 2025). Despite the challenges in maintaining social relationships, all participants relied upon partners, friends, older children and/or family for necessary support for managing children and households. The necessity for social support and challenges with social relationships sometimes produced relational tensions. Research highlights that a reliance on partners as an immediate source of support is common for mothers with

chronic illnesses (Power et al., 2011) and many people find benefit from having socially supportive relationships (Sirotiak et al., 2026).

It was these same struggles that also made it difficult for participants to continue paid work opportunities, and all participants at one point were forced to stop working. For those attempting to return to work, flexible work options were greatly valued (managed return to work programmes, flexible hours and work from home conditions). Similar research on long COVID has identified workplace flexibility as an important feature for successfully continuing to work (Smith et al., 2025a). Difficulties for people with long COVID to continue working with the same abilities and productivity levels prior to falling sick have also been acknowledged by New Zealand literature (Jeffreys et al., 2024). Furthermore, some of the participant's partners also stopped working to care for young children and the family were reliant upon disability support services, but these were described as "*not enough to live on".* Although limited, New Zealand research has identified that financial stressors significantly impact the lives of people with long COVID, including reluctance to access support from medical clinics due to their cost (Russell et al., 2023). Financial stress and a lack of support options contributed to a sense of isolation and feeling overlooked by the health system, one participant described this as *"we fall through the disability cracks".* This finding is in alignment with other research, albeit in a Canadian context, that has identified that attempts to access disability assistance with long COVID is a stressful and overwhelming experience (Smith et al., 2025a).

It was experiences with stigma and medical gaslighting that also became a barrier for participating in social lives. Many participants recounted experiences with family, friends, acquaintances and health workers who criticised their illness experience and/or reduced legitimate struggles to the psychological battles of "laziness". Some participants began to avoid social settings to avoid experiencing the stigma from people who judged them and/or blamed them for falling ill with long COVID. The limited research and medical uncertainty around long COVID symptoms continue to create an environment whereby stigma, criticism and social judgement flourish. Evidence for experiences of gaslighting are plentiful within long COVID research (Ladds et al., 2020; Lieberwerth & Niemeijer, 2024; Moretti et al., 2022; Russell

et al., 2022; Smith et al., 2025a) including within New Zealand (Rhodes & Douglas, 2025). Long COVID researchers have described this illness as one where people "ironically must expend considerable amounts of energy to have their condition acknowledged…with family, friends, employers and health care professionals" (Mendenhall et al., 2025, p. 1). For some participants, this left them wanting to hide their long COVID diagnoses to avoid triggering hearing unhelpful controversial and judgemental criticisms. Interestingly, the desire to hide medical diagnoses in order to avoid stigma is a common occurrence within academic literature. For example, research in Europe (Moretti et al., 2022) and the UK (Clutterbuck et al., 2024) highlight the pressures people with long COVID hide their illness to avoid its associated stigma. Additionally, Harrison et al. (2024) discuss how some participants avoid discussing symptoms in order to avoid feeling dismissed and disbelieved. Researchers understand this as a protective behaviour whereby people with long COVID are aware they may encounter controversy and stigma, so they avoid discussing their illness as a means of self-protection (Pantelic et al., 2022a). The proclivity for isolation and hiding symptoms also exists across other contested and stigmatised illnesses, such as fibromyalgia (Colombo et al., 2025) and chronic fatigue (Donalek, 2009).

Research shows that mothers experience positive outcomes with good social and tangible support networks, particularly when support values the importance of maternal identity (Peters & Skirton, 2013). This research highlights that long COVID disrupted and changed many aspects of their social and financial lives; finances were negatively impacted and social lives were contracted. Public and institutional stigma was constantly dealt with from families, friends, workplaces, and medical settings. These experienced lead to internalised stigma and avoidance of social situations. The impact of this on mental health and sense of self is discussed below.

5.1.3 Psychological: Mental Health and Sense of Self

All participant's experienced poor mental health as a consequence of living with long COVID. Multiple interacting features of the experience worked together to contribute to low mood and anxiety. Shrinking social circles, missing former lifestyles and hobbies all contributed to a sense of isolation and loss. Much of this was related to not being able to parent in the way they had or had visualised prior to falling sick. Some

of this was also felt around a reliance on others for help and support. Low mood was also particularly contributed to by experiences of social stigma (internalised, anticipated and enacted stigma) and medical gaslighting, which specifically contributed to participant's feelings of being misunderstood, dismissed and overlooked. The particular nature of long COVID as an illness with an uncertain future and limited medical support/treatments contributed to a sense of anxiety and uncertainty in the participants. Increased anxiety from the uncertainty of long COVID along with the incidence of depressive symptoms are both a feature of prior research on long COVID (Engelmann et al., 2024), including research in New Zealand (Russell et al., 2022). Research on mother's experiences with multiple sclerosis also highlight the increased stress and challenging nature of living with an illness of uncertain future (Özkan & Polat Dünya, 2023).

All participants experienced an altered sense of self due to their illness which was primarily associated with lost functional abilities due to fatigue, brain fog and pain. Other long COVID research has also identified the loss of identity in association with changes to reduced physical functioning and independence (Humphreys et al., 2021; Russell et al., 2022). Physical limitations affected the participant's sense of self as productive workers and active individuals who engaged in exciting hobbies and lives. Instead, long COVID reduced the participant's sense of self to "*boring*" people who no longer could be "*fun and exciting*" parents to their children. Reduced abilities to feel like good mothers only added to an already poor state of mental health for many. This finding is in alignment with prior research that indicates mothers can tend to feel increased guilt and poor emotional wellbeing considering the impact their illness has on their family (Smith et al., 2025b). Changes to how the participants viewed themselves were unexpected results of having long COVID, some responded to this with denial and/or grief. Research by Kennelly et al. (2023) has also found that people with long COVID experience changes in their identity as a grieving process, as people come to terms with the widespread impacts of their illness.

For most participants, mental health was negatively impacted by long COVID. However, some participants discussed what helped them feel a greater sense of positive wellbeing. Social supports from partners, friends and family all contributed to

improve the participant's sense of emotional wellbeing through their illness. Additionally, time spent playing and interacting with their children were important for the participants to feel a sense of vicarious joy. For many, the emotional benefits from having support were essential to living day-to-day with long COVID. Additionally, some participants discussed the value they experienced in having mental health therapy to help them cope and adjust to the challenges of long COVID. Unfortunately, some participants also discussed how they would like to have therapy, but it was not financially accessible to them at the time.

It was important to note that some, not all, participants also experienced "*unexpected positives"* from reflecting on their time living with long COVID. Each participant was in a different stage of recovering and coping with their illness. This meant that some had found the mental space to reflect on what they had learnt for the better, while many others were still grappling with the disruptive changes. For those who discovered positive learning, life perspectives were reoriented to be more in line with their values, this was often reprioritising their family unit, health and wellbeing. It is not unusual for difficult life experiences, like chronic illness, to generate positive learning despite their struggles. Research by Duzen et al. (2026) highlights how a range of families with parents experiencing chronic illness (e.g. diabetes, kidney and rheumatic disease) experienced stronger ties to one another and a sense of growth through the illness journey. Additionally, recent long COVID research has shown people have experienced changes to their life values and worldviews, (i.e. morals and religious beliefs) either for better or worse since falling ill (Sirotiak et al., 2026).

Considering the various ways they manifested for each participant, the psychological impact of living with long COVID was a significant component of the experience for everyone. Physical changes, disruption to mothering roles and long COVID stigma were the main drivers of low mood for these participants.

5.2 Intersecting Features of Long COVID in Motherhood

5.2.1 A Lifestyle and Identity Disruption

Living with long COVID was often described by the participants as having disruptive effect on their mothering abilities and sense of self. In this way, the findings of this thesis support the concept of biographical disruption (Bury, 1982) whereby lifestyles and identity are overhauled during the experience of long COVID. Functional limitations from symptoms required mothers to adapt their mothering within the boundaries of this new illness. Fatigue, brain fog and pain were often discussed as significant symptoms that created challenges to meet children's needs and to provide safe, fun and exciting home environments. For example, mothers experienced difficulties from a lack of energy to cook meals for their children, clean and tidy homes, entertain, and physically interact with their children. Mothers often talked about adapting their parenting with various techniques, these included a reliance on technology to entertain kids, house-wide baby monitors, low energy activities (e.g. lay-down play time) and for one mum, reliance on a nanny. A common feature for these participants was a negative sense of self from their inabilities to be "*fun and exciting mum[s]"* that they hoped they would be. The restrictions of living in sick bodies contributed to mother's feelings of missing out on participating in their children's lives. This contributed to guilt, worry and sadness for some. Participants drew upon language consistent with good mothering ideologies (Schmidt et al., 2023), by often describing how their long COVID mothering negatively affected their sense of self as good mothers. Instead, long COVID disrupted their usual mothering approaches and mothers worried over being seen by others and by themselves as 'bad parents.'

The concept of chronic illness causing a biographical disruption to mothering lifestyles and identity is not new, previous research supports this concept in mother's experiences of cancer (Dorgan et al., 2013) and multiple sclerosis (Parton et al., 2019; Parton et al., 2018) as just two examples. The notion of long COVID having a disruptive force on people's lives also exists within prior research (Pearson et al., 2022), however this thesis extends this concept to long COVID in motherhood. Specifically, that this life stage of motherhood adds additional complexities to the disruption of falling ill with this

new illness. Furthermore, this disruptive effect of falling ill with long COVID affected seven domains within the theoretical life phase of matrescence (biological, psychological, social, cultural, economic, moral and existential) (Athan, 2025; Slootjes & DeRolf, 2025). This thesis therefore supports a holistic understanding of the diverse areas of motherhood that seem to be affected by living with long COVID.

5.2.2 Long COVID in Motherhood: A Social Role Conflict

The disruptive consequences for these mothers falling ill with long COVID might be understood within the concept of conflicting social roles. Thorne (1990) has previously suggested various competing demands and social obligations between the role of 'mother' and the 'chronically ill person'. This research by Thorne (1990) has identified that mothers experience contradicting expectations for how they should be good mothers and patients. Specifically, expectations for mothers to be self-sacrificial (often at the expense of their own health and wellness) stand in stark contrast with expectations for sick people to devote their energy to rest, recovery and health-supportive behaviours (Thorne, 1990). When these two social roles of 'mother' and 'chronically ill person' coexisted, the participants sensed the conflicting expectations and their tensions.

The concept of conflicting social roles was evident when all participants discussed difficulties enacting the main piece of long COVID medical advice, which was to lie-down and rest. Participants discussed feeling guilty and/or upset when participating in self-care behaviours, such as resting in quiet dark rooms, when they felt that they should have been present with their children. One mother explicitly explained the guilt she felt from sitting on a park bench resting instead of playing with her son on the playground. Other participants also expressed how they felt that their need for rest came at the cost of being separate from children, which led to worries over being 'bad' parents and missing out on motherhood. Some mothers rested less than they knew they needed in order to gain a sense of positive wellbeing from playing and spending time with children. There was a general sense of stress, worry and failure for prioritising their own needs, over the needs of being present and involved with their children. In this sense, rest did not always feel beneficial due feelings of guilt and worry. Experiences of guilt and worry within mothering are consistent with research that highlights these as

common emotional experiences for mothers (Sutherland, 2010; Williamson et al., 2023).

The competing demands between the prioritisation of rest for long COVID recovery and the mother's guilt in doing so, is an example of "priorities that were characteristically at odds" with mothers trying to do their best for their families (Thorne, 1990, p. 216). The demands placed on mothers for caregiving are often all-consuming and leave little energy and time to focus on rest and self-care (Riley et al., 2025). Despite knowledge that conserving and pacing energy are important tools to manage long COVID symptoms, the competing obligations for mother's caregiving adds challenging complexity (Riley et al., 2025). Among the limited research specifically exploring these intersections, Aghaei et al. (2022) and Spence et al. (2023) similarly suggest that the experience can be understood as a conflict of social roles. Specifically, the expectations for mothers as primary carers for the home and children are challenged when also trying to manage their own needs and symptoms (Aghaei et al., 2022). Aghaei et al. (2022) conceptualises the challenging nature of caring for families during long COVID as "conflicts related to the family roles" (p. 8). Difficulties for people to enact social roles once falling ill with long COVID has been previously described by participants with a sense of "guilt, grief and loss" (Leggat et al., 2024, p. 8). This is consistent with other research highlighting that mothering role conflict can lead to a sense of poor mental health and wellbeing in long COVID (Ryan et al., 2025).

Outside of long COVID, research in various other chronic illnesses during motherhood also highlight the challenges and struggles of limitations to physical and mental abilities which impede on mothering activities. Mothers with fibromyalgia have expressed "remorse and frustration" at the inability and/or difficulty of managing childcare expectations (Briones-Vozmediano et al., 2016, p. 836). Research on mothers with cancer has also explored tensions between the social role of 'mother' and 'sick person' adding further complexities to the lives of mothers (Mazurek, 2024).

The concept of mothers finding it challenging to balance the competing demands of self-care and childcare has been identified in the context of other chronic illnesses (Mackenzie, 2014) and also motherhood in general (Barkin & Wisner, 2013). Researchers often discuss these challenges within the dominant norms for good

mothers to be self-sacrificial, fully involved and attentive to children (Dorgan et al., 2013; León-Herrera et al., 2025; Nichols et al., 2015). Additionally, mothers have often been discouraged for enacting self-care, and those who do prioritise their needs are often judged poorly against the expectations for good mothers to not be self-indulgent (Riley et al., 2025). These stereotypes and expectations for good motherhood seem to particularly harm recovery and management for these women with long COVID. This is supported by research on other chronic illnesses where mothers recall uncomfortable experiences with medical professionals who further perpetuate and internalise good mother norms during patient-practitioner encounters (Milman & Sternadori, 2024).

These tensions between motherhood and self-care, can be understood as contributing to pressures for mothers to "push through" their fatigue, pain and stress. The experience of pushing through often compromised their own needs for rest with the needs of their children, and this often led to burn out and energy crashes. Existing literature has also explored the concept of people pushing through long COVID symptoms due to various societal and cultural expectations (Leggat et al., 2024; McDuff et al., 2025). In their study, Smith et al. (2025a) describe the societal pressures of "suck it up culture" which contributed to participants pushing past their energy limits in order to avoid being perceived as "lazy" or having "failed" productivity for slowing down and resting (p. 4). Experiences of pushing through illness symptoms to meet cultural and social norms are also common for women in other chronic illnesses such as lupus (Bam & Lulema, 2025) and chronic pain conditions (Sheppard, 2020). Unfortunately, pushing through tended to exacerbate symptoms (Leggat et al., 2024), and contribute to burn out. Pressures for participants to push through their long COVID symptoms was also challenging when participants desired to "do more in daily life" (McDuff et al., 2025, p. 11). The participants in McDuff et al. (2025) gave up various social roles (i.e. work and leisure) so they could better manage their energy availability. However, their study did not focus on social roles that are more difficult and/or impossible to give up, such as parenthood.

Disruption and conflict between social roles are additionally problematic in the context of illnesses that are contested and stigmatised, including other illnesses like chronic fatigue (Thorne et al., 1997). On top of pressures to adapt their mothering

approaches with good mothering ideologies, the participants also experienced stress from living with a stigmatised and uncertain illness. This meant participant's often spoke of tensions in social relationships which people who could not accept the legitimacy of long COVID either as a diagnosis or as a legitimately disabling chronic illness. Additionally, participants discussed social expectations for motherhood to be naturally exhausting, thereby minimising the legitimacy of long COVID fatigue and contributing to social pressures to "push through" symptoms. Therefore, mother's experiences within their social relationships and sense of self were full of conflict and tension. These tensions were added to by the uncertain future for full or partial recovery from illness.

5.3 Recognising the Challenges of Long COVID in Motherhood

This thesis supports the need for wider recognition of long COVID's debilitating impacts across multiple facets of life (social, financial, work, recreational, and familial). Many long COVID researchers have called for greater recognition of long COVID within society and healthcare as a disabling illness (Hereth et al., 2022; Motilal et al., 2025; O'Brien et al., 2023). This means that within long COVID research, partnership between medical and disability studies is needed (Hunt, 2023). However, current long COVID care in New Zealand is not coordinated or formalised (Ministry of Health, 2025). Enhancing public and medical awareness of long COVID's debilitating consequences has the added benefit of improving knowledge to improve lived experiences and counter stigma (Smith et al., 2025a). Additionally, the participant's experiences of long COVID address seven domains of matrescence (biological, psychological, social, cultural spiritual, economic, moral, existential) (Athan, 2025; Slootjes & DeRolf, 2025) which supports these as specific areas of need for long COVID within the life phase of motherhood.

Furthermore, this thesis supports the concept that the challenges of living with long COVID have added complexities within motherhood. The findings of this thesis support gender inclusive healthcare approaches for those seeking to support mothers with long COVID. Existing literature supports enhancing tailored approaches that take gender and social roles into account within the long COVID experience, such as O'Brien

et al. (2025) who call for “gender-sensitive approaches” to long COVID care (p. 425). Health professionals should appreciate the complexities that motherhood adds onto the experience of chronic illness considering the “compromises and conflicts” that exist between these two social roles (Thorne, 1990, p. 219). This thesis supports the use of the biopsychosocial model as one way to consider the complexities of long COVID in motherhood.

Healthcare that incorporates medical advice in light of the various social roles that people inhabit are important for developing valuable patient-centred and specific recommendations (Thorne, 1990). Long COVID support services that validate the intersecting complexities of motherhood are important if research and healthcare are to move on from a historically gender-neutral perspective on chronic illness and disability services (Thorne et al., 1997). Specific recommendations for gender inclusive long COVID support have been outlined by which include treatment approaches that address the caregiving responsibilities and demands that mothers often face (Riley et al., 2025). Specifically, targeted interventions for women with caregiving and/or work responsibilities alongside their long COVID may include flexible services that can accommodate caregiving demands (e.g. telehealth, flexible service hours and opportunities for childcare support) (Riley et al., 2025). The authors also recommend prescribing rest, self-care and opportunities for supported household assistance (Riley et al., 2025). Additional interventions include the need for community/informal support networks to help support mothers with role tension in long COVID, this has also been previously suggested for mothers who experience role tensions in academia (CohenMiller & Demers, 2019). In these ways, this thesis supports a gender and social role inclusive approach to improving mother’s experiences within long COVID.

5.3.1 Additional Practical Recommendations

The findings from this thesis support practical suggestions to improve knowledge and support for long COVID in motherhood. The participants often discussed suggestions that they would like to see to improve their experience of long COVID in motherhood. Table 3 outlines recommendations discussed by the participants and are supported by their quotes.

Table 3

Practical Recommendations

Impact Area	Recommendations	Example Quote
Workplace	Flexibility within workplaces (i.e. work from home options, reduced hours and managed return to work schemes, workplace income protection insurance schemes)	"My employer has been phenomenal…my boss who had family experience of like cancer treatment and chronic illness and just had a real lived experience of what this journey was like, encouraged me to take months off at a time to try and get better" "Having [workplace] income protection insurance was game changing" "They appointed an occupational therapist…she was then put in charge of my return-to-work plan…I had this really slow gradual return to work…having this plan in place has been really amazing"
Healthcare	Medical recognition for long COVID's debilitating impact, with improved healthcare education to enhance medical awareness and advice for patients Integrated allied healthcare options for long COVID support (e.g. occupational therapy, psychology, physiotherapy) with specific support from people with lived experience of chronic illness	"Knowing that there is support and that you're recognised, because long COVID and chronic fatigue are not recognised and they're not a disability and, in some places, not even a long-term chronic illness" "The information that is given really shaped a real fast downward spiral and impacted my health even more… 'this is incurable, we don't know anything about it, and you have to do nothing'…if I had any kind of hopeful information…even that would have helped" "I did this chronic pain workshop at the health clinic here…they have like a rheumatology and some physio, and they have this two-week program for people with chronic pain and they and recently opened it up to long COVID" "I've had an amazing system having a chronic illness therapist who had lived through chronic fatigue"

Impact Area	Recommendations	Example Quote
	Provision of better official guidance for long COVID recovery and healing	"My doctor would have given me some better information to start off with rather than just being like …'you probably need to rest for a bit'...there wasn't much research, there wasn't any like official guidance…I wish I knew how to properly rest and how to properly heal"
	Improve mental health service access tailored for people with long COVID	"I really believe that therapy would seriously help people with long COVID…if we had the budget I would have gone back to therapy to deal with this now"
Public Health Messages	Public health communication to improve awareness and provide helpful information, specifically to also combat long COVID stigma and dismissal	"Just somewhere to go to find official helpful information on what [long COVID] might look like and what are some things that you could do that might help rather than just a generic 'rest and look after yourself'"
		"I think it would help a lot of people in my position if…the powers that be in society accepted it…so things like research and surveys and anything that helps get acknowledgement and recognition I think is really important"
Systems Level	Streamlining DSL and WINS service accessibility and system navigation for improved disability support access (financial support, housework support, occupational therapy home supports, childcare supports, support for solo-parents etc.)	"I know this is available in some other countries or maybe with some particular illnesses, is like help to clean the house…particularly when you have a child…that kind of practical help would have really taken a load off"
		"It's so hard to get support and I really had to fight for the nanny and the support worker…knowing there is support would have helped so much"
		"…the inconsistencies and not knowing where the heck you can go and what is the best route or scenario…it's just a whole world of unknowns that you have to navigate…the system's like completely backwards and it's so hard to navigate"
		"I am sure there are things out there that would help me, but financially we don't have access to them…we fall through the disability cracks, it's not an accident so you don't get ACC, it's not a disability according to the funding people"

The participants largely pointed to system level changes such as better education for health care professionals, more medical understanding, and easier access to financial and other supports. These suggestions have been shown in other contested health conditions such as fibromyalgia (Colombo et al., 2025) and chronic fatigue (Pilkington et al., 2020). However, what the participants do not often mention was support for mothers, which may reflect difficulties that mothers face in seeking support systems without risking their sense of self as good mothers (Budds, 2021). Overall, these suggestions highlight the value of wrap-around support at all three biopsychosocial levels to support daily living and potential recovery, as identified by these mothers with long COVID.

5.4 Study Limitations and Directions for Future Research

With a commitment to the methodological principles of IPA, this thesis sought a small homogenous sample. This meant that all participants were similar in age, diagnosis, length of illness and ethnicity (New Zealand European). This means that the findings are not generalisable to the larger population of mothers living with long COVID in Aotearoa New Zealand. Instead, the findings explore the lived experiences of the five participants involved within their unique life contexts. Despite the generalisability of the findings not being appropriate in this research context, theoretical transferability is (Smith et al., 2022). Smith et al. (2022) outline that the consumers of IPA research can consider the findings within their own "experiential knowledge base" to consider broader implications and the transfer of knowledge applied into new contexts (p. 32). Therefore, readers should avoid generalising these findings to make claims about the wider population, instead they can transfer ideas and concepts to consider them in new alternative contexts and other life worlds of people living with long COVID in motherhood.

With the limited breadth of current qualitative literature exploring the experiences of long COVID in motherhood there is the potential for a lot more research. Future research that explores the intersections of mothering and long COVID experiences for people of Asian, Pasifika, and the indigenous ethnic group, Māori, are valuable considering the experience of culture influences understandings of health and

illness (Durie, 1985). Additionally, future research could explore diversities in the experiences of long COVID in motherhood by considering symptom diversity, those without formal diagnoses, mothers of various ages, partnerships and ages of children. Furthermore, this thesis only considered people from the long COVID registry, however the experiences of people with long COVID who live in rural, isolated and/or those without internet/technology access may be disadvantaged by a lack of familiarity with the registry and thus are less likely to have access to similar research opportunities. Therefore, future research that targets hidden social groups is likely valuable to gather diverse accounts of lived experiences with this under-researched illness. This is particularly important considering researchers have called for a focus on lived experience research to form the foundation for meaningful support and long COVID treatment guidelines (Abercrombie & Hitch, 2025; Gorna et al., 2021). Additionally, future quantitative research can be useful to validate the exploratory insights from qualitative research to produce conceptual tools and models to guide supports for mothers with long COVID.

5.5 Conclusion

Considering the objectives for this thesis project, the lived experiences of long COVID in motherhood are diverse and complex. Commonalities from experiential accounts suggest that motherhood poses additional challenges for those who live with this chronic illness. Disrupted lifestyles and a sense of self from the physical and mental limitations of being ill were lifechanging realities. The participants' internalised expectations for good mothering ideologies and the often-gendered nature of childcare and housework, conflicted with the needs of their sick bodies to rest and heal. This led to guilt, worry and anxiety. Long COVID is a contested and stigmatised illness with invisible symptoms which added additional complexities for the participants to navigate social landscapes. This thesis supports the legitimacy of long COVID in motherhood as a debilitating experience which can affect multiple physical, social and psychological facets of life. Therefore, this thesis contributes to the existing corpus of literature that can guide future research and the development of practical insights to support mothers living with this new and complex illness.

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Appendices

Appendix A: Project Advertisement

Appendix B: Participant Information Sheet

The Lived Experience of Long Covid in Motherhood

INFORMATION SHEET

Researcher's Introduction

My name is Ashley Barea, and I am a postgraduate student at Massey University undertaking an MSc in Health Psychology. This project is my master's thesis.

Project Description and Invitation

As New Zealand seeks to evolve and learn from our COVID-19 pandemic experience, my thesis looks at the emerging and currently under researched illness of long Covid within the stage of early motherhood. I am looking for five to seven mothers with children under the age of five who are interested in sharing their stories of living with long Covid while also being a mother. I hope to find mothers who wish to participate through the University of Auckland's Long Covid Registry.

The focus of this research is to explore the experiences of having long Covid during the first five years of motherhood. This study offers New Zealand mothers the opportunity to share their stories and experiences navigating life and coping with this chronic health condition through two interviews via Zoom. Interviewing can be flexible depending on your commitments, symptoms of fatigue/concentration and childcare. Interviews can include a combination of shorter Zoom conversations and answering written questions via email. We can discuss how this might look for you.

To participate in this project, you must meet these criteria:

- Self or Medical diagnosis of long Covid
- Currently a mother of at least one child under five-years-old
- 18 years or older
- Proficient in English
- You must identify that you feel well enough, physically and psychologically, to take part and that discussing your experiences will not cause significant distress.

The exclusion criterion for participating in this research is:

- Currently receiving treatment for post-natal depression

Project Procedures

I would like to invite you to take part in two interviews with myself via Zoom at times and dates best suited to you. I can work around your schedules and childcare arrangements. Each interview will last roughly one hour and to minimize your fatigue, must be at least

one day apart. The total time for participation in this project will be about 2.5 hours. You will receive a $50 voucher after the first interview as an acknowledgement of your time, effort and stories.

If this project sounds like something you might be interested in, I invite you to a brief (no more than 15 minutes) phone call to discuss the project and answer any questions you may have. The interviews can take place at any time that best suits you, and you will receive a copy of the interview questions before this time.

There are minimal risks to participant in this project, however it is important to recognize that talking about your personal experiences may unintentionally cause distress, since long Covid and mothering can be difficult experiences. Your well-being is very important to me, and I will do my best to support you. We can always pause the interview, skip questions or you can withdraw from the project. I can also check in with you following the interviews, if you wish. We do encourage you to use any support systems you may already have in place, and I can provide contacts for local mental health support services.

After our interviews, you will be given the chance to review a written copy of our conversation (the transcript) and change your responses to ensure your experiences are represented in a way you approve. You will have the opportunity to withdraw from the study at any time until 2-weeks after you have been given the opportunity to review/amend your transcript.

Data Management

Interviews will be audio and video recorded so I can create a written copy of our conversation. These will be deleted after you have the chance to amend your transcript and approve of the way your experiences are represented. Only I (and my supervisor) will know the names of anyone taking part in this study. All personal information discussed in our interview will be removed in your transcript and your name will be replaced with a pseudonym (fake-name). Your transcripts and data will be stored on the Massey OneDrive, which is the most secure form of storage we have available. Your data will be stored for five years maximum and deleted. Upon completion of my project, you can receive a summary of project findings if you request them.

Participant's Rights

You are under no obligation to take part in this study. If you decide to participate, you have the right to:

- decline to answer any questions.
- withdraw from the study at any time up until 2-weeks after receiving your transcript to review.
- ask any questions about the study at any time during participation.
- be given access to a summary of the project findings when it is concluded.

- ask for the recorder to be turned off at any time during the interview.

Project Contacts

- Researcher: Ashley Barea
    - Email: [redacted]

- Supervisor: Dr Kathryn McGuigan
    - Email: K.Mcguigan@massey.ac.nz

Please contact the researcher and/or supervisor if you have any questions about participating in this project.

Long Covid Support

For more information on long Covid and Supports in New Zealand please visit:

- Long Covid Support Aotearoa:
    - Website: https://longcovidsupport.co.nz/
    - Their Facebook Support Group: https://www.facebook.com/groups/nzlongcovid/

- Website for Health New Zealand Te Whatu Ora: https://info.health.nz/conditions-treatments/infectious-diseases/covid-19/long-covid

This project has been reviewed and approved by the Massey University Human Ethics Ohu Matatika 1, Application OM1 25/29. If you have any concerns about the conduct of this research, please contact the Chairperson, Massey University Human Ethics Ohu Matatika 1, email humanethics1@massey.ac.nz

Appendix C: Consent Form

The Lived Experience of Long Covid in Motherhood

PARTICIPANT CONSENT FORM

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

Please highlight your answers:

I agree/do not agree to the interview being sound recorded.

I agree/do not agree to the interview being image recorded.

I wish/do not wish to have my recordings returned to me.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: ..... **Date:** .....

Full Name - printed .....

Appendix D: Interview Schedule

Interview Schedule

Start:

- Thank you so much for being here and your willingness to share your experiences and have a chat with me. I really appreciate it. How has your day been so far?
- Our convo is likely to go for about an hour, but no longer than 1 hour and a half.
- If at any point, you'd like to take a break during our chat or would like to skip a question, ask me any questions or stop the interview please feel free to do so. Your comfort is my priority, so feel free to grab a cup of tea to sip on while we chat.
- No such thing as a wrong answer, it's your experiences I'm interested in.
- Our conversation will be made totally anonymous afterwards when I make a transcript.
- Questions before we begin? Would you like to grab a cup of tea/coffee before our chat?
- Okay to begin recording?
- Let's begin with some quick demographic questions: age, ethnicity, occupation, age of children, are you parenting with a partner? Medical or self- diagnosis of long COVID?

1. The Journey into Motherhood

- Can you tell me about your journey to become a mum?
  - When did this begin?
  - What was it like transitioning to become a mum?
    - How did it feel?

2. Finding out you have long COVID

- Can you tell me about when you discovered you might have had long COVID?
  - When was this in relation to becoming a mum?
  - What was that experience like?
    - Thoughts, feelings.
  - What made you think it was long COVID?
  - How did you feel about maybe having long COVID?
  - What did you do?
  - Can you tell me about the symptoms you have?
    - Can you tell me more about what it is like to live with these symptoms?

        - Earlier on, did you have any expectations for what you thought living with long COVID might be like?
            - How does this compare to the reality?

3. **Impact on Lifestyle**
    - Can you tell me about how long COVID has affected you in your life, specifically as a mother?
        - Socially, mentally, physically, spiritually, financially?
        - In what ways has your lifestyle been influenced?
        - What are the impacts long COVID has on the tasks involved with being a mum?
            - Can you remember an occasion when your experience of long COVID affected you as a mum?
            - In what ways/how?
            - How did that make you feel?
            - What did that mean for you, experiencing that?
        - Has living with long COVID influenced your expectations for motherhood as a whole?
            - If so, how?
            - Has long COVID influenced how you envision what being a mum will be like in the coming years?
    - Have there been any expected / unexpected difficulties that you encountered?
        - If so, can you tell me more?

4. **Impact on Self**
    - Has having long COVID influenced the way you see yourself?
        - i.e. as a mum, as a partner, as a woman?
        - If so, in what ways?
        - Can you think of a specific/recent example where you felt you're your illness influenced how you see yourself?
        - Has your view on life changed since long COVID?
            - In what ways? For better or worse?
        - Has your view on other people changed since long COVID?
            - In what ways? For better or worse?

5. **Your Experience of Support**
    - Can you tell me how you cope with your long COVID?
        - Socially, mentally, emotionally, physically, financially?
        - How has this experience of coping been for you?

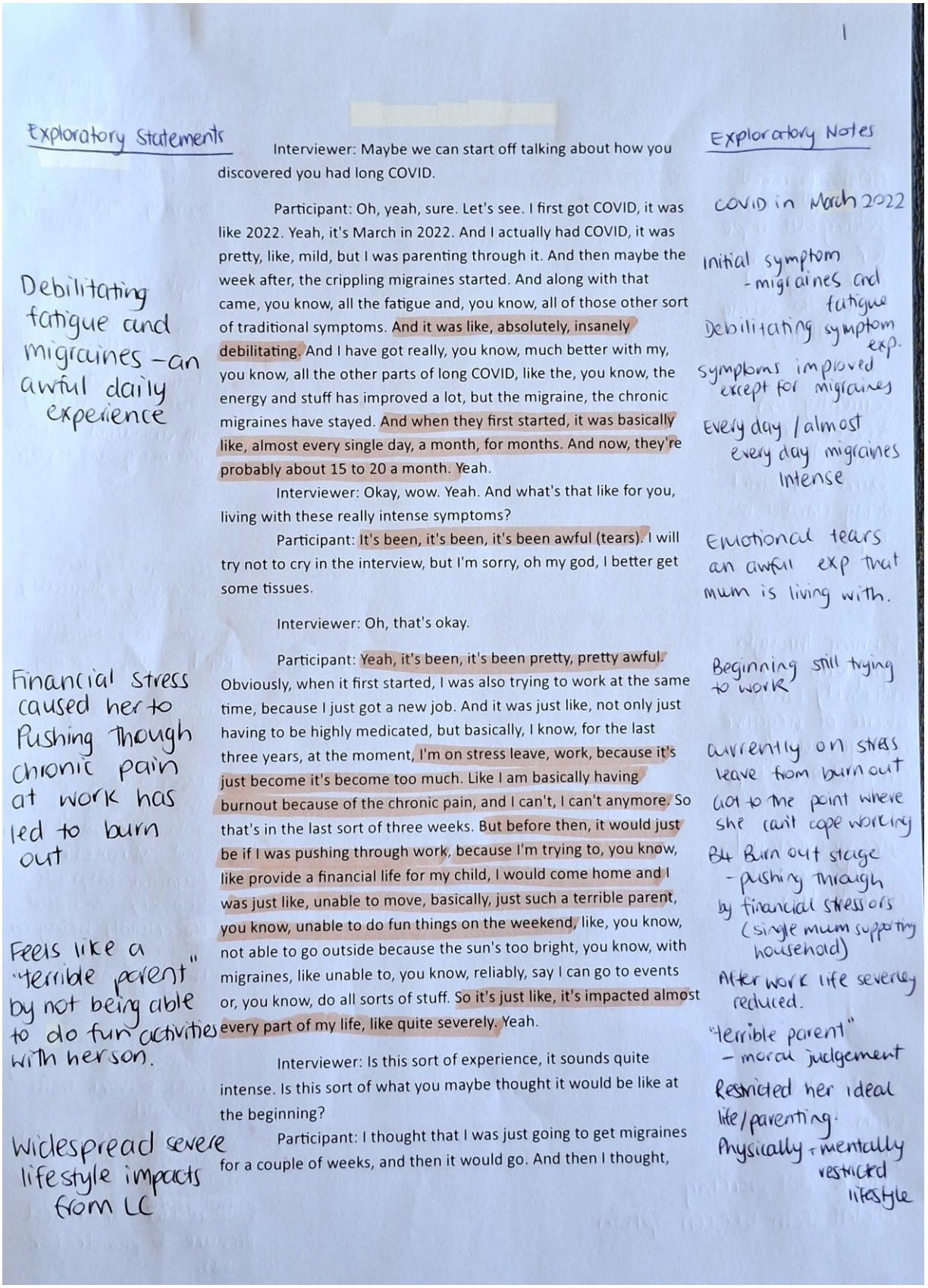
        - How does it feel?
    - What do you think would help you to cope better?
        - Physically, mentally, spiritually, socially?
    - What does coping with long COVID mean to you?

6. **Closing question**
    - Before we head to close the interview, can you tell me about what you enjoy most about being a mum?

7. **Anything you'd like other people to know about your experiences living with and coping with long COVID as a mum?**

8. **Closing of the interview project:**
    - **Thank them for their time**
    - **Any questions before we end.**
    - **Reminder of $50 Prezzee voucher (mail or online).**
    - **Instructions to expect an email with the transcript for their editing and instructions for voucher reimbursement.**

Appendix E: Excerpt of Exploratory Notes and Statements



Exploratory Statements

Interviewer: Maybe we can start off talking about how you discovered you had long COVID.

Participant: Oh, yeah, sure. Let's see. I first got COVID, it was like 2022. Yeah, it's March in 2022. And I actually had COVID, it was pretty, like, mild, but I was parenting through it. And then maybe the week after, the crippling migraines started. And along with that came, you know, all the fatigue and, you know, all of those other sort of traditional symptoms. And it was like, absolutely, insanely debilitating. And I have got really, you know, much better with my, you know, all the other parts of long COVID, like the, you know, the energy and stuff has improved a lot, but the migraine, the chronic migraines have stayed. And when they first started, it was basically like, almost every single day, a month, for months. And now, they're probably about 15 to 20 a month. Yeah.

Interviewer: Okay, wow. Yeah. And what's that like for you, living with these really intense symptoms?

Participant: It's been, it's been, it's been awful (tears). I will try not to cry in the interview, but I'm sorry, oh my god, I better get some tissues.

Interviewer: Oh, that's okay.

Participant: Yeah, it's been, it's been pretty, pretty awful. Obviously, when it first started, I was also trying to work at the same time, because I just got a new job. And it was just like, not only just having to be highly medicated, but basically, I know, for the last three years, at the moment, I'm on stress leave, work, because it's just become it's become too much. Like I am basically having burnout because of the chronic pain, and I can't, I can't anymore. So that's in the last sort of three weeks. But before then, it would just be if I was pushing through work, because I'm trying to, you know, like provide a financial life for my child, I would come home and I was just like, unable to move, basically, just such a terrible parent, you know, unable to do fun things on the weekend, like, you know, not able to go outside because the sun's too bright, you know, with migraines, like unable to, you know, reliably, say I can go to events or, you know, do all sorts of stuff. So it's just like, it's impacted almost every part of my life, like quite severely. Yeah.

Interviewer: Is this sort of experience, it sounds quite intense. Is this sort of what you maybe thought it would be like at the beginning?

Participant: I thought that I was just going to get migraines for a couple of weeks, and then it would go. And then I thought,

Debilitating fatigue and migraines - an awful daily experience

Financial stress caused her to Pushing though chronic pain at work has led to burn out

Feels like a "terrible parent" by not being able to do fun activities with her son.

Widespread severe lifestyle impacts from LC

Exploratory Notes

COVID in March 2022

Initial symptom - migraines and fatigue

Debilitating symptom exp.

Symptoms improved except for migraines

Every day / almost every day migraines Intense

Emotional tears an awful exp that mum is living with.

Beginning still trying to work

Currently on stress leave from burn out got to the point where she can't cope working

But Burn out stage - pushing through by financial stressors (single mum supporting household)

After work life severely reduced.

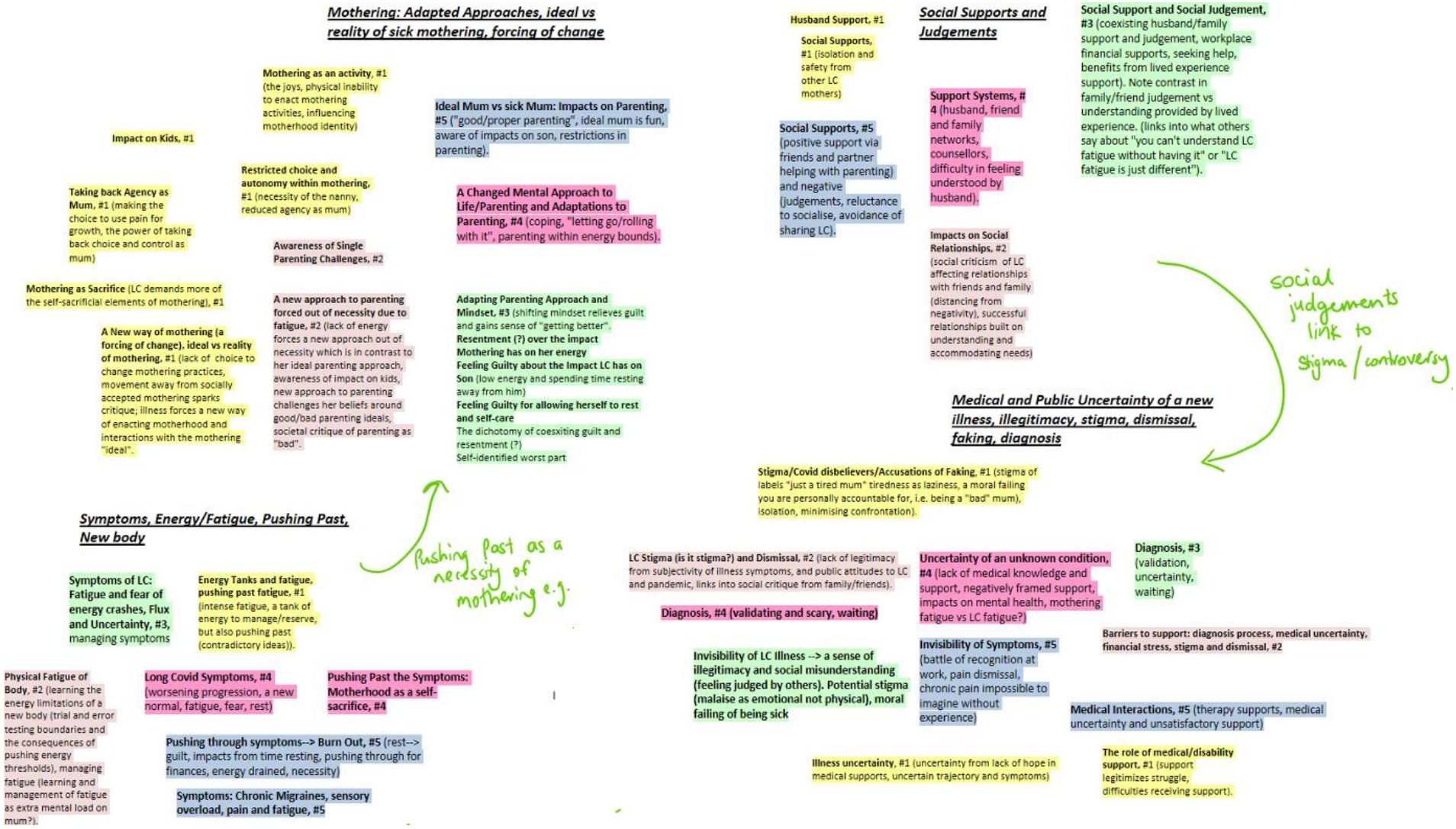
"terrible parent" - moral judgement

Restricted her ideal life/parenting.

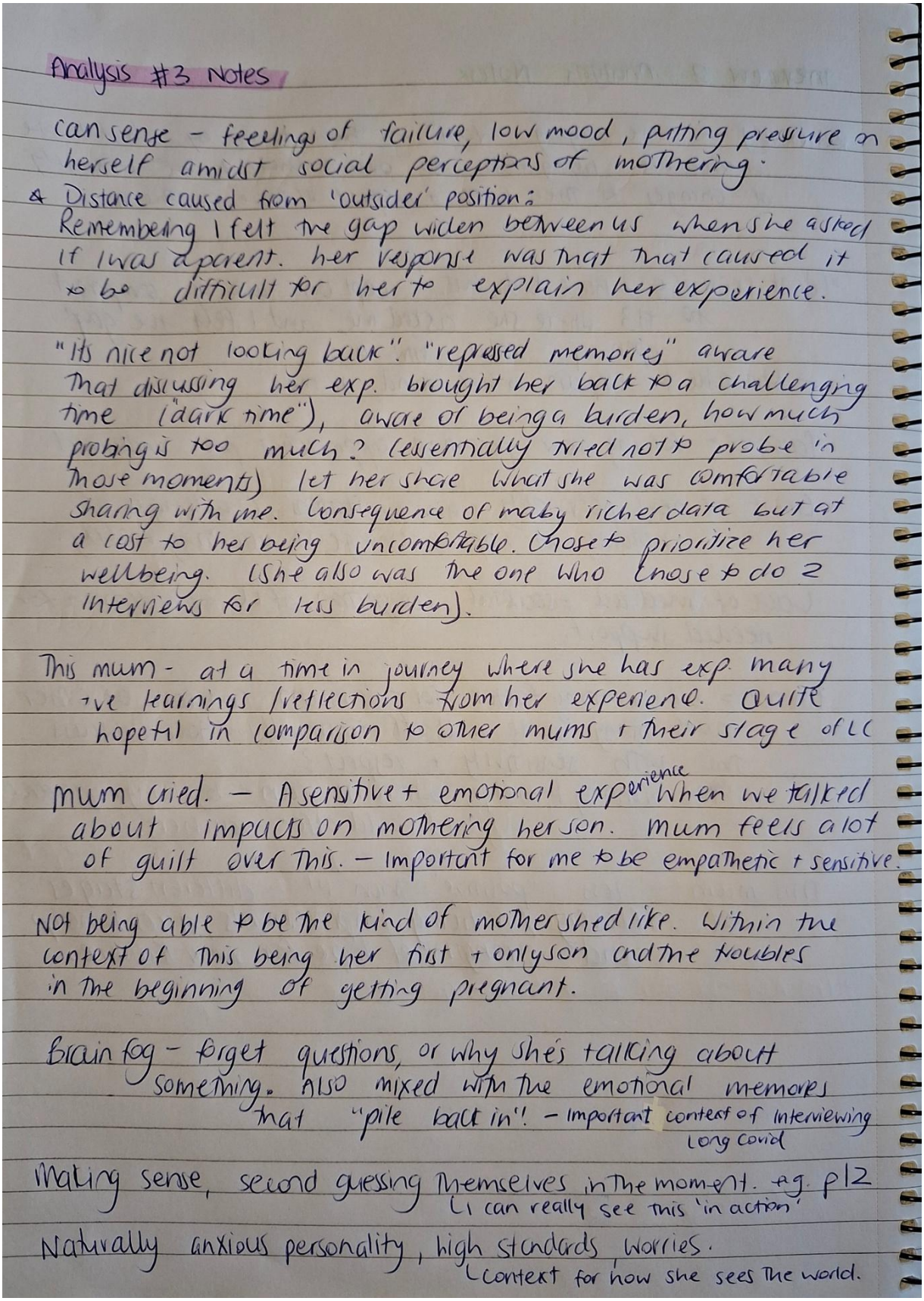
Physically + mentally restricted lifestyle

Appendix F: PETs Excerpt for Jane

Appendix G: GETs Excerpt



Appendix H: Excerpt from My Reflection Dairy



Analysis #3 Notes

can sense - feelings of failure, low mood, putting pressure on herself amidst social perceptions of mothering.

* Distance caused from 'outsider' position:
Remembering I felt the gap widen between us when she asked if I was a parent. her response was that that caused it to be difficult for her to explain her experience.

"Its nice not looking back". "repressed memories" aware that discussing her exp. brought her back to a challenging time ("dark time"), aware of being a burden, how much probing is too much? (essentially tried not to probe in those moments) let her share what she was comfortable sharing with me. Consequence of maby richer data but at a cost to her being uncomfortable. Chose to prioritize her wellbeing. (She also was the one who chose to do 2 interviews for less burden).

This mum - at a time in journey where she has exp. many +ve learnings / reflections from her experience. Quite hopeful in comparison to other mums + their stage of LC

mum cried. - A sensitive + emotional experience when we talked about impacts on mothering her son. mum feels a lot of guilt over this. - Important for me to be empathetic + sensitive.

Not being able to be the kind of mother she'd like. Within the context of this being her first + only son and the troubles in the beginning of getting pregnant.

Brain fog - forget questions, or why she's talking about something. Also mixed with the emotional memories that "pile back in"! - Important context of interviewing Long covid

making sense, second guessing themselves in the moment. e.g. p12
(I can really see this 'in action'

Naturally anxious personality, high standards, worries.
(context for how she sees the world.