Citation: Bradley, C. (2024). The Experience of Recovered Anorexic Mothers, Caring for Their Anorexic Daughters: A Qualitative Study. (Unpublished Doctoral thesis, City, University of London)

In the Shadow of Anorexia: Mothers, Daughters, and the Struggle to Heal

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Portfolio Submitted in Partial Fulfilment of the Requirements for the Professional Doctorate in Counselling Psychology (DPsych)

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June 2024

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List of Abbreviations

AMHS - Adult Mental Health Services
AN - Anorexia Nervosa
BPS - British Psychological Society
BMI - Body Mass Index
BN - Bulimia Nervosa
BED - Binge Eating Disorder
CAMHS - Child and Adolescent Mental Health Services
CBT-E - Enhanced Cognitive Behavioural Therapy
CP - Counselling Psychology/Counselling Psychologist
DSM - Diagnostic and Statistical Manual
ED - Eating Disorder
EDNOS - Eating Disorder Not Otherwise Specified
ES - Experiential Statements
FBT - Family-Based Therapy
GETS - Group Experiential Themes
GP - General Practitioner
ICD - International Classification of Diseases
IPA - Interpretative Phenomenological Analysis
IPT - Interpersonal Therapy
MANTRA - Maudsley Model of Anorexia for Adults
MDT - Multidisciplinary Team
MH - Mental Health
NED - Non-Eating Disordered
NICE - National Institute for Health and Care Excellence
NHS - National Health Service
PC - Primary Care/Primary Caregiver
PETS - Personal Experiential Themes
PTSD - Post Traumatic Stress Disorder
RCT - Randomised Control Trials
SE - Socio-Economic
SH - Self-Harm
SSCM - Supportive Clinical Management

Acknowledgements

I would first like to express my deepest gratitude to the six participants who generously gave their time, and entrusted me with their experiences. Hearing your stories was a privilege, and without you this research would not have been possible. I am truly grateful.

I would also like to thank my research supervisor, Dr Daphne Josselin. Your unwavering support, thoughtful guidance, genuine enthusiasm for the project, and unfailing patience have been invaluable, and your dedication to challenging and pushing me to achieve my best, has been crucial in getting this portfolio to where it needed to be. I will be forever thankful to you for helping me see this through.

Thank you to my cohort. Sharing this experience with such a kind, caring and supportive group of people really made some of the more challenging times manageable, and I feel incredibly fortunate to be leaving with some lasting friendships.

To my friends, who can't quite believe I did this. Thank you for all of your support and encouragement throughout the last three and a half years, but especially the last few months, when I needed it the most.

Henry, the last three and a half years have been challenging, both personally and professionally, but you have been there supporting me every step of the way, from the day I received my offer, to submission day. Your sacrifices, selflessness, and patience have not gone unnoticed. I am so grateful, and I cannot wait to have our weekends back!

Finally, to my family. Grandma, thank you for your pride in my achievements, interest in my work and your love, you have been, and continue to be, such an important presence in my life. As was Poppa, who is with me every day. Dad, thank you for your check-ins, encouragement, and motivation, and in particular, your support throughout my final year. I am not sure how I would have managed without it, and for that I am so grateful. Mum, there has not been a day in which you have not unconditionally supported or believed in me. I am who I am because of you, and I am eternally thankful for everything you have done that has enabled me to reach this point. I truly could not have done any of this without you.

Declaration

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PREFACE

The following doctoral portfolio is comprised of three components: a research study, that seeks to explore the experience of recovered anorexic mothers, caring for their anorexic daughters; a combined client study/process report, that presents a piece of my own clinical work with a young client with anorexia; and a publishable paper, that focuses on one of the main themes generated in the original research study. Although they are separate pieces of work, they all share the common theme of eating disorders, and anorexia nervosa more specifically.

The first section consists of a qualitative research study, that sets out to explore the experience of recovered anorexic mothers, caring for their anorexic daughters. Anorexia Nervosa (AN) is considered to be the longest standing, and most dangerous of all identified eating disorders (ED) (Arcelus et al., 2011), and has a mortality rate higher than that of any other psychiatric disorder (NICE, 2017), affecting women more adversely, who make up 80-90% of those diagnosed (Smink et al., 2012). The typical age of onset for women is adolescence, typically between 15-19 years of age, and as a result the demanding, distressing role of caregiver often befalls parents (Fox et al., 2015). The idea for this project developed through my interest in the carer experience. Given the high heritability rates for these disorders (Rikani et al., 2013), I wondered what this experience may be like if caregivers themselves had received a diagnosis, and upon the somewhat surprising discovery that little information surrounding this phenomenon existed, the research question emerged: "what is the lived experience of a recovered anorexic mother, caring for her anorexic daughter?". The present study thus aimed both to fill a gap in the literature, and to provide a platform for mothers in this poorly understood population, to share their experiences of their unique caregiving role. Six participants took part, and data from the interviews were analysed using Interpretative Phenomenological Analysis (Smith et al., 2009). While the findings support existing research that has showed the immense difficulties and distress that caregivers may experience, they also provide novel understanding of the additional challenges, and helpful insight, that caring with a historical diagnosis may bring. The implications for Counselling Psychology, clinical practice, and future research are discussed.

The second section is a combined clinical case study and process report taken from my final year on the professional doctorate. It explores my client's presentation of, and journey with AN, and my use of the transdiagnostic form of CBT 'Enhanced Cognitive Behavioural Therapy' (CBT-E) as a treatment approach, paying particular attention to my ability to collaboratively develop a CBT-E formulation, and to reflect on my own clinical work. My professional and personal development was significantly impacted by the work with this client. This was my first client with severe AN, my first experience using this treatment approach, and the work gave me my first insight into the complexities of multidisciplinary teamwork, all of which only reaffirmed my desire to work with EDs, and to contribute to improving the professional support available to those with EDs.

The third and final section of the portfolio is a journal article that draws upon one of the most novel and seemingly important Group Experiential Themes generated in the original research study – 'Mother's own AN experience – A double edged sword'. The findings outline how having personal experience of AN can influence aspects of a mother's role as carer, including how possessing a greater understanding can be helpful (and not so helpful), and how it can present additional challenges and health risks. The results are discussed again in relation to existing literature, and areas of future research are explored. I hope to submit the article to the *Journal of Health Psychology,* as it aligns with the journal's aim of integrating research and practice by publishing research that not only advances our theoretical understanding, but also has practical implications for clinical and health practices, policies, and interventions, something I hope to have achieved with the article and wider research project. The journal also has global reach, therefore my hope is that the study will be disseminated to professionals on a large scale.

Taken together, these three pieces shed light on the complexities and challenges of having AN, caring for someone with AN, and managing the latter with experience of the former. It highlights the underacknowledged importance of the caregiver role, and the desperate need for improvements within the healthcare system, so as to reduce what sometimes seems an unnecessary escalation of the illness, and mitigate the subsequent strain on the caregiver, their family, and NHS resources. I sincerely hope that the unique experiences of each participant are conveyed, and their voices heard, and that the importance of considering caregiver needs, as they provide essential support to their child, is clearly expressed.

Over the last few years I have developed both personally and professionally, learning about theory and practice, and have had the privilege to experience what it is like to be part of a client's therapeutic process. As I researched the carer experience, I was saddened to hear distressing accounts from the participants in this study. However, I was also able to see just how much of an impact it is possible for Counselling Psychologists to have, both academically and clinically. As a result, I feel inspired and even more determined to use my position as a qualified Counselling Psychologist to make an impact on the field, alongside my day-to-day clinical work, and it is my hope that this study is my first step in doing so.

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PART A

Research Study

The Experience of Recovered Anorexic Mothers, Caring for Their Anorexic Daughters: A Qualitative Study

ABSTRACT

The most dangerous type of eating disorder, Anorexia Nervosa (AN), presents with a lifetime prevalence in women of 2 to 4% and a notably high risk of fatality in teenage girls. Research has shown that caring for a daughter with AN can be experienced as all-consuming. However, despite evidence that genetics contribute significantly to the risk associated with developing an eating disorder, little is known about how this role may be experienced by a mother who has previously experienced AN herself. This research therefore set out to explore the lived experience of recovered anorexic mothers, caring for their anorexic daughters.

Six participants were recruited, from whom data was collected through individual semi-structured interviews. The chosen analytic strategy was Interpretative Phenomenological Analysis, and the following six Group Experiential Themes were generated: ‘Watching the anorexia take over’, ‘Healthcare – A broken system’, ‘A heavy emotional and physical toll’, ‘A strained home and family life’, ‘Mother’s own AN experience – A double edged sword’, and ‘Caring for a daughter with AN – Surviving the role’. Taken together, these findings highlight the profound and inherent challenges that accompany the role of carer, from watching their daughter be consumed by the illness, to the emotional and physical impact on both themselves and their family. Critically here, the participants’ own experience of AN appeared to create additional difficulties, though it could also be experienced as providing helpful insight into the condition. The findings also suggest an urgent need for improvements in the support and healthcare available to both mother and daughter, and emphasise the importance of timely intervention.

1 INTRODUCTION AND LITERATURE REVIEW

1.1 Introduction

This piece of research seeks to explore how a mother with a history of anorexia nervosa (AN), experiences caring for her anorexic daughter. In light of what is already known about the carer experience for mothers from the multitude of existing literature (E.g. Poser, 2005; Fox et al., 2017), the high prevalence of AN in adolescent girls (Smink et al., 2012), and the growing knowledge we have surrounding the intergenerationality of eating disorders (EDs) (Trace et al., 2013), this under-researched phenomenon was deemed a vital area of exploration. It is hoped that this will help to better equip Counselling Psychologists (CP) with the knowledge needed to support these mothers, and improve the overall quality of ED care offered, that is needed by a growing population (van Eeden, 2012). The chapter begins with an overview of AN, including definitions, diagnosis, prevalence, aetiology, and treatment. The reader will then be introduced to the existing literature on the parental caring experience, both with and without an ED, my relationship with the research, and ultimately how all of the above led to the formation of the research question, and rationale for the study.

1.2 Overview of Anorexia Nervosa

1.2.1 Definitions and diagnosis

Eating disorders (EDs) have been described as a disturbance in eating behaviours that is persistent and severe, causing a change in food consumption or absorption, leading to health or psychosocial impairment and distress (American Psychiatric Association [APA], 2013). It is estimated that EDs affect 1.6 million people in the United Kingdom (Joint Commissioning Panel for Mental Health, 2020). Several EDs are identified in the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-5; APA, 2013), and the eleventh revision of the International Classification of Diseases (ICD-11; World Health Organisation, 2019), including bulimia nervosa (BN), binge-eating disorder (BED), avoidant/restrictive food intake disorder (ARFID), and other specified feeding or eating disorders (OSFED). Anorexia nervosa (AN)[1] however, is considered to be the longest standing and most dangerous (Hoek & Hoeken, 2003; Auger et al., 2021), presenting with a mortality rate higher than that of any other psychiatric disorder (Arcelus et al, 2011; NICE, 2017;

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[1] Often simply called ‘anorexia’.

Edakubo & Fushimi, 2020), with more than five percent of sufferers dying within four years of diagnosis, and a high number of deaths seen in adolescents specifically[2]. Women and girls that are 15 – 24 years old are estimated to be at a 12 times higher risk of death from AN than from all other causes combined (Smink et al., 2012).

AN is a term that has been used for approximately 140 years (Gull, 1874), however it was not until many years later that it was officially included in the diagnostic classification systems known as the Diagnostic and Statistical Manual of Mental Disorders (DSM), published by the APA, and the International Classification of Diseases (ICD), published by the World Health Organisation. Although AN symptoms were included in the DSM-I, published in 1952, they were conceptualised within a psychophysiological reaction framework (Dell'Osso et al., 2016); and it was only in the DSM-III (1980) that an official ED section was added, which included AN with its own diagnostic criteria. Similarly for the ICD, AN was not included until the ninth revision in 1979 (World Health Organisation, 1979).

Current diagnostic criteria in both international classifications are similar, with the DSM-5 (2013) requiring the following: i) significant energy restriction relative to requirements, resulting in severe weight loss and dangerously low body weight in relation to sex, age, physical health and developmental trajectory; ii) a considerable fear of becoming fat, gaining weight, or persistently engaging in behaviours that interfere with gaining weight; and iii) a disturbance in the way one experiences one's body shape or weight, which also has an undue influence on self-evaluation, or a persistent inability to view or recognise dangerously low bodyweight. Denial of the severity of the illness is common (Starzomska & Tadeusiewicz, 2016). The ICD-11(2019) too requires a significantly low body weight, persistent restrictive eating patterns with a link between body weight and self-evaluation, and inaccurate perception of one's size. It also includes however, that low body weight could be replaced by rapid weight loss if all other criteria are met, and notes a preoccupation with body shape and weight that is excessive.

Medical and psychiatric co-morbidities are often present (Zipfel et al., 2015), and include depression, anxiety, and obsessive-compulsive disorder. Autism Spectrum Disorder, while classified as a neurodevelopmental disorder, is also becoming more frequently observed. Traits associated with both OCD and ASD, such as rigid thinking patters, preference for routine, and

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[2] Up to half of the fatalities seen are said to be attributed to suicide, and the remaining stemming from starvation-induced medical complications, most commonly cachexia, circulatory failure, and multiple organ failure (Westmoreland et al., 2022; Fichter & Quadflieg, 2016).).

compulsive behaviours, can exacerbate the restrictive behaviours seen in AN, complicating the presentation of AN and making treatment more challenging (Huke et al., 2013; Marucci et al., 2018).

Of those that survive, the likelihood of achieving full recovery is just 50% (Steinhousen, 2002; Eielsen et al., 2021), with Strober (2010) stating that the one fact that is uncontroversial about AN is that quick resolve is rare, with many remaining chronically ill for over a decade (Ratnasuriya, 1991; Duriez et al., 2021). This chronic form of AN, sometimes known as severe and enduring anorexia (SE-AN) (Touyz, 2015; Downs et al., 2023), is experienced by at least a third of sufferers (Eddy et al., 2017); and sees enduring AN symptoms, recurrence, and relapse, years after initial diagnosis, despite periodic episodes of remission or partial recovery (Miskovic-Wheatley, 2023). Contributors to relapse may include significant life transitions, body image concerns, and stress (Federici & Kaplan, 2007). Treatment efficacy is variable, and dependent on various factors including co-morbidity presentations, AN severity, characteristics of treatment received, readiness or motivation for change, and experience when initially seeking treatment, with particular regard to the stigma in the medical community (Miskovic-Wheatley, 2023). This stigma is often seen among GPs, with research showing that they often hold misconceptions about EDs, that can result in misdiagnoses, symptom dismissal, or delays in appropriate intervention, which can ultimately exacerbate and/or catalyse the course of illness (Haigh & Treasure, 2003; Robinson et al., 2012). Overall, research suggests treatment success rates for full recovery are between 40 – 70%, (Hay et al., 2014; Steinhausen, 2002). However, given the complex and relapsing nature of AN, access to follow-up and ongoing psychological support, and long-term care, are often essential for effective management and relapse prevention (Pike, 1998; Giel et al., 2021).

It is worth noting that EDs in adolescents can differ significantly from those in adults with regard to precipitating factors, presentation, progression, and treatment. For example, adolescence is a period characterised by heightened vulnerability due to developmental changes and challenges, such as puberty, peer pressure and the process of identity formation, which can amplify any body image concerns and contribute to the emergence of restrictive or disordered eating behaviours (Herpertz-Dahlmann, 2015). AN at this life stage will therefore often coincide with critical development stages, making early intervention essential. The malleability of the adolescent brain and behaviours also means that they have a greater likelihood of increased responsiveness to early treatment, offering better prognoses (Abrams, 2022).

In contrast, adults often present with more chronic and entrenched symptoms, as the illness may have remained untreated or poorly managed for a longer period. This chronicity can result in additional complications, such as prolonged malnutrition, organ damage, and a higher prevalence of comorbid psychiatric conditions, including depression and anxiety (Zipfel et al., 2015). Adults may also experience difficulties overcoming the long-term cognitive and behavioural patterns associated with their disorder, often requiring more intensive and long-term treatment approaches compared to adolescents. Furthermore, the social factors influencing eating disorders differ between these groups. While adolescents are often heavily influenced by peer relationships and family dynamics, adults may face challenges related to work, intimate relationships, and parenthood, all of which can exacerbate or perpetuate the illness (Fairburn & Harrison, 2003). These distinctions underline the importance of tailoring treatment approaches to the specific developmental and social needs of each age group.

1.2.2 Prevalence

Anorexia does not discriminate, affecting individuals of all genders, ages, and backgrounds. However, prevalence of the disorder varies within differing demographics. Literature documents that men experience AN, and have a reported lifetime prevalence between 0.3 – 0.5% (Paterson, 2008; Hudson et al., 2007). Research has shown AN to affect women more adversely however, experiencing a lifetime prevalence of between two and four percent, whilst making up 80-90% of those diagnosed (Smink et al., 2012; Neale & Hudson, 2020). Furthermore, despite AN affecting individuals across the lifespan, as mentioned previously, the most common age of development is during adolescence and young adulthood, with the aforementioned gender disparity particularly high at this stage (Ward, 2019). Recent trends highlight an increase in incidences among younger girls under the age of 15, as well as older adults, with it being suggested that a high risk period for the recurrence or onset of AN is during peri-menopause (van Eeden et al., 2021; Samuels et al., 2019). The most common age of onset in males is less clear than their female counterparts, with some studies suggesting a comparable or slightly higher age of 16 years, whilst others report a younger peak at 12-13 years (Petkova et al, 2019; van Eeden et al., 2021) [3].

AN presents in all ethnicities and socio-economic (SE) populations, despite once being coined ‘the disease of affluence’ (Huryk, 2021), with status not deemed to be an illness predictor. However

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[3] A rise in AN cases has been seen across all ages in recent years however (Micali, 2009), perhaps due to increased awareness and subsequent reduction in stigma, alongside the substantial impact that the COVID-19 pandemic had on case numbers (Gao, 2022).

socio-cultural factors such as ethnicity and race that may overlap with SE status are often overlooked (Huryk, 2021), needing further investigation. Those of lower SE status appear to face increased barriers when attempting to seek treatment (something discussed further into this chapter), suggesting that the prevalence of SE-AN could be present due to delays in receiving initial treatment (Ali et al., 2020). Newly developing research has also suggested that those in the LGBTQ+ community are at a greater risk of developing AN (Parker & Harriger, 2020).

It is important to note that the statistics presented here are likely an underestimation, as not every individual seeks treatment, particularly men (Räisänen & Hunt, 2014), due to the double stigma of not only having a psychiatric disorder, but a "female-specific" disorder (van Eeden et al., 2021, p. 517). Furthermore, some do not have their illness detected by their General Practitioner (GP) (Waller, 2014).

1.2.3 The aetiology of AN: A brief outline

Like for many mental health (MH) difficulties and psychiatric disorders, the aetiology of AN is complex and multifactorial, with causality often being deemed a combination of environmental, sociocultural, psychological, and biological factors (Woerwag-Mehta & Treasure, 2008). 'Environmental' can be considered an umbrella term for many factors, and may include influences from an individual's surroundings, such as dynamics within the family, peer influences, traumatic events, or societal pressure. A psychological contribution to the development of AN, is said to stem from pre-existing traits or cognitive processes, such as those associated with low self-esteem, perfectionism, anxiety disorders, depression, or obsessive-compulsive disorder (Anderluh et al., 2003). Reducing food intake can also be seen as a coping mechanism, to gain back some form of agency and control, for instance after experiencing a trauma (Malecki et al., 2018).

Sociocultural factors bear reference to broader societal influences, including cultural attitudes and norms, representation of body image in the media, and sociological behaviour and values. For example, cultures that place emphasis on appearance, or promote and glorify being thin, such as Western societies (Lee, 1996; Polivy et al., 2022), may heighten the risk of anorexia development. A similar trend could be seen within professions enforcing pressure to be thin, for instance modelling, ballet, and certain sports, notably those which emphasise aesthetics or low body weight (Francisco, 2018; Anderson-Fye & Becker, 2004). Regular exposure to the presentation of the 'thin ideal', and false portrayal of appearances through digital alteration across media platforms, can increase body dissatisfaction (Spettigue & Henderson, 2004), thus further contributing to the risk of

AN. Support is garnered for the role of sociocultural factors when looking at the global prevalence of AN. AN is currently considered a significant public health concern in many Western countries, including the UK, the United States, Canada and Australia, with lifetime prevalence rates ranging from 0.9% to 4% in women, and 0.1% to 0.5% in men (Paterson, 2008; Hudson et al., 2007; Hay et al., 2015), yet a much lower prevalence is seen in non-Western countries and societies such as the Middle East, Asia and Africa, seeing rates of 0.1% to 1.5% in women, and 0.1% to 0.2% in men (Qian et al., 2021; van Eeden et al., 2021)[4]. These rates are seen to be slowly approaching Western prevalence however, likely influenced by exposure to Western media and subsequent cultural shifts (Pike & Dunne, 2015).

The role of biology in AN development continues to be explored. However, it is believed to involve physiological vulnerabilities and neurobiological differences (Woerwag-Mehta & Treasure, 2008). In recent years, more research has been conducted, exploring the role of genetics, and AN has been found to be highly heritable (Rikani et al., 2013), with EDs appearing to ‘cluster’ in families (Klump et al., 2001). A 28-58% heritability rate has been shown to be present in twin studies, and according to Hildebrandt & Downey (2013), one is 12 times more at risk of developing the illness if a first-degree relative of someone suffering with AN. Further support is provided by Trace et al (2013), who found that 40-50% of the risk associated with ED development, was accounted for by genetics. In the context of the transgenerational aspect of AN aetiology, but beyond biological inheritance, research suggests that the intergenerational transmission of trauma, and behavioural and emotional patterns, such as parental attitudes towards body image or food, can significantly shape children’s perceptions, and therefore potentially heighten their susceptibility to AN (Chapman et al., 2024). Furthermore, epigenetic factors (environmentally driven changes in gene expression), through similar factors also play a critical role, and would further compound risk (Kaver et al., 2024). This highlights a complex interaction between genetic predisposition and familial environmental influences, and therefore emphasises the importance of intergenerational dynamics in understanding the aetiology of AN.

1.2.4 Treating anorexia

The serious, complex and multifaceted nature of AN makes treatment particularly challenging, and typically warrants a multidisciplinary team (MDT) approach, providing psychological, nutritional, and/or medical care to address both the psychological and the physical symptoms (Fogarty et al.,

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[4] Prevalence data for AN in non-Western countries is more difficult to establish due to cultural differences in recognition, reporting, and stigma surrounding EDs (Pike & Dunne, 2015).

2016). In the UK, treatment is typically offered via a tiered system, and may be conducted in various settings dependent on severity, such as with physicians or GPs (primary care), various outpatient services, day treatment (secondary care) or residential programs, and partial or full hospitalisation (tertiary care) (APA, 2006). Public (typically through government funded healthcare services such as the NHS), and private (e.g. self-funded or through private healthcare providers) treatment options are available, and the earlier the intervention, the higher chance of a lasting recovery (Treasure & Russell, 2018).

According to the National Collaborating Centre for Mental Health (UK) (2004), there is no agreed or uniform approach to the treatment and management of AN, and for adults particularly, no evidence to support the notion that any one treatment is superior to another. For adolescents however this is not the case, with Family-based Therapy (FBT), also known as the Maudsley Model, being deemed more effective than individual therapy for adolescents and children with AN (Espie & Eisler, 2015) who are fit for outpatient treatment and medically stable (Rienecke, 2017). It involves familial collaboration, seeking to empower parents to adopt a primary role in the facilitation of their child's recovery (Lock & le Grange, 2013). FBT has shown rates of full recovery of up to 90% (le Grange, & Eisler, 2009), with numerous additional control trials and empirical evidence in support of its effectiveness for the treatment of adolescent AN (e.g. Lock & le Grange, 2013; Schmidt et al., 2007; Lock et al., 2010). The next best line of treatment is considered to be CBT-E or Adolescent-focussed Psychotherapy if for whatever reason FBT is not an option (Stillar et al, 2022).

The models of treatment most commonly used with adults, as suggested by the National Institute of Health and Care Excellence (2017), are Enhanced Cognitive Behavioural Therapy (CBT-E), the Maudsley Anorexia Nervosa Treatment for Adults (MANTRA), and Specialist Supportive Clinical Management (SSCM). Evidence and support for the use of group therapy, Focal Psychodynamic Therapy (FPT), Cognitive Analytic Therapy (CAT), and Interpersonal Therapy (IPT), is also developing (APA, 2006).

CBT-E, the approach believed to be disseminated most widely (Fairburn, 2008), is a time limited, transdiagnostic intervention, understanding EDs as resulting from distorted cognitions, problematic and maladaptive behavioural cycles and habits, and dysfunctional beliefs (Wilfley et al., 2011), and seeks to address and restructure patterns of thinking and daily behaviours that perpetuate the illness (Stillar et al., 2022). A great deal of evidence supports in CBT-E aiding the improvement of AN (e.g. Pike et al., 2003; de Jong et al., 2020), however statistics regarding its efficacy are still limited.

One study however, discovered that 65.5% of participants who received CBT-E met the remission criteria, compared to 33.3% in IPT (Fairburn et al., 2015), with others concluding that if delivered well, those not significantly underweight (more than half of adult cases) achieve full, maintained remission (Dalle Grave, 2022). Underweight individuals see a similar rate of remission; however approximately only 65% complete treatment (Fairburn et al., 2013).

MANTRA, specifically designed for AN treatment, is an adaptation of FBT for use with adults (Schmidt & Treasure, 2006). It is a manualised modularised treatment involving elements of CBT, motivational interviewing, and writing tasks, focussing on addressing individuals’ underlying maintenance mechanisms (Startup et al., 2021). Central to MANTRA, is its’ foundation in the interpersonal cognitive model, a theoretical framework that focuses on the interactions between cognitive processes and interpersonal relationships, proposing that cognitive, interpersonal, and socio-emotional difficulties, act together to both cause and maintain AN (Wittek et al., 2021).
It is collaborative, flexible, and individualised based on the needs of each individual, and may include behavioural experiments, aiming to increase motivation for recovery, and addresses thinking styles or socio-emotional impairments (Schmidt et al., 2012). The efficacy of MANTRA continues to be explored, however several studies have found the approach to show not only stable and significant improvements in the psychopathology of AN and BMI, but also low drop-out rates and high acceptability of treatment (Schmidt et al., 2015).

Developed initially as a placebo comparison treatment, SSCM exceeded expectations and is now deemed no less effective than IPT or CBT-E (McIntosh et al., 2023). However it is still a novel, lesser-known approach. Supportive psychology and clinical management approaches are combined, aiming to aid in the normalisation of eating and returning to a healthy weight, whilst addressing additional life challenges (Kiely, 2022). Practitioners adopt a supportive, optimistic, and positive stance (McIntosh et al., 2023). The effectiveness of SSCM remains unclear, with a scarcity of outcome information. However randomised control trials (RCTs) have found it to aid weight gain, the symptoms of AN, and overall psychological functioning (e.g. McIntosh 2016; Schmidt et al., 2015). One RCT saw SSCM outperform other targeted treatments, with a more comprehensive evaluation of psychopathology (McIntosh et al., 2005).

In the UK, several steps are typically involved in treatment pathways. Initially, individuals or families tend to seek support from their local GP or family doctor, who provides an initial assessment and referral, if needed, to NHS specialist services such as specialist ED clinics, community MH services, or inpatient units (NICE, 2017). From here some individuals or families may choose to go privately, or continue with the NHS. Signposting through other avenues may also occur, for example through MH charities, school counsellors, or online organisations such as Beat Eating Disorders which offer support groups, helplines and information resources to aid in the navigation of the treatment process. Whilst CBT-E and MANTRA are effective, they face challenges in reaching hard-to-reach communities, something deemed important to address (as discussed on pages 26 and 134). Accessibility is a key issue, as both models rely on trained professionals, which can be scarce in rural or underserved areas, and while CBT-E has begun incorporating telehealth options to broaden access, MANTRA has fewer such adaptations, further limiting its reach (Linardon et al., 2017). Cultural relevance is another concern, as both models were developed in Western contexts and may not fully resonate with non-Western communities, where MH stigmas and expressions of EDs may differ (Paslakis et al., 2023). Additionally, financial barriers can impede access, especially for economically disadvantaged individuals, with the cost of sustained treatment being prohibitive for many. Both models also tend to focus on individualized care (Jansingh et al., 2020), potentially neglecting the benefits of community-based or peer-supported approaches, which might better suit hard-to-reach populations. Addressing these limitations through cultural adaptation, cost reduction, and integrating community support could enhance their reach and impact.

It is important to note that if you enter treatment as a child, it is likely to be provided by Child and Adolescent Mental Health Services (CAMHS), which cater up to 18 years old only; therefore a transition to adult MH services may be necessary if treatment is still needed after reaching adulthood. Furthermore, geographical location can significantly impact available care, for instance due to differing healthcare structures, demand for care, or having a local specialist service. As explored in the subsequent literature review, it can be a challenging time for those around an individual with AN, and MDTs play a crucial role in supporting and providing care for families (NICE, 2017), which may include psychoeducation, involving the family in treatment plans, or signposting them to parental/caregiving support groups (Treasure et al., 2020). Overall, a holistic approach to treatment, addressing the needs of both families and the individual with AN, is important for the promotion of recovery and long-term well-being.

1.3 Literature review: the parental experience of caring for a child with anorexia

Caring for someone with a complex, life-threatening illness such as anorexia is highly challenging (Zipfel, 2015), and with the average age of onset being in adolescence, typically around 15-19 years of age, the role of caregiver often befalls family members, most commonly, parents (Fox et al., 2015). Given that AN is characterised by high heritability and chronicity over the life span, parent caregivers may themselves have had a diagnosis of AN. This literature review therefore aimed to investigate and evaluate existing research into the parental experience of caring for a biological child with AN[5], followed by a particular focus on research looking at the experience of parents with a personal history of AN.

Through the electronic databases PsychINFO, Google Scholar, and PubMed, in 2021, a first narrative literature review was conducted. The initial wording of searches surrounded the more general parent experience of caring for a child with AN, and included ‘parental experience of child with anorexia nervosa’, ‘caring for a child with anorexia’, ‘caring for someone with an eating disorder’, followed by combinations of the following; ‘carer’, ‘caring’, ‘anorexia nervosa’, ‘caregiver’, ‘daughter’, ‘son’ ‘experience’, ‘parent experience’, ‘mother, ‘father’, ‘anorexia’, ‘eating disorder’ [6]. The time brackets for publication were 1995-2023, selected on the basis of capturing the most relevant studies. The abstracts of the results generated were read to establish relevance, with those deemed irrelevant subsequently excluded. Reference lists of all selected studies were then manually searched, to ensure the amount of literature reviewed was sufficiently broad. All identified studies were manually entered into an Excel document, facilitating systematic organisation and categorisation based on themes, methodology, sample etc. Approximately 146 papers were screened, and 42 were retained and used in the review.

Five themes emerged from the review of the selected literature: ‘family life was affected’, ‘emotional impact’, ‘social impact’, ‘health professionals and services’, and ‘positive impact’.

1.3.1 Family life was affected

The considerable impact on the family dynamic and home life that caring for a child with an ED has, was discussed by many studies, with parents describing how the family had been manipulated and consumed when caring for a child with AN specifically (E.g. Poser, 2005; Whitney et al., 2005; Karlstad et al., 2022). Findings supporting this arose from Cottee-Lane and colleagues’ qualitative study (2004), that looked to explore the experiences of seven mothers and four fathers caring for

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[5] From this point forward, any reference to 'mothers,' 'daughters,' or other familial relationships will refer to biological relationships, unless otherwise specified.

[6] Although the review focused on anorexia, occasional references to the co-morbid presentation of BN were included due to the severity and risk that can accompany it, the regularity of this occurrence, and the occasional overlapping of symptoms (Mussell & Mitchell, 2001). Any other EDs referenced in the DSM-V were omitted from the search, such as BED, or OSFED, unless referenced under the broad umbrella term of ‘eating disorders’ as they are less critical in nature, and there is little literature.

their child with early onset AN through the use of semi-structured interviews and Interpretative Phenomenological Analysis (IPA). Participants shared how a sense of normality no longer remained at home, describing home life as a “living nightmare”. Diversity in the sample was lacking however, a common theme throughout the literature (e.g. Stitt & Reupert, 2014; Chapman, 2023; Hoskins & Lamb, 2002), as all participants had professional occupations and were Caucasian, something deemed a limitation, as we know that AN exists in various social and cultural backgrounds (Dolan, 1991). The prevalence of this limitation in the literature, highlights a need for qualitative research into more hard-to-reach groups and communities, so as not to neglect the lived experiences of these individuals.

The literature has also reported, that whilst having a child with AN can have a detrimental impact on many elements of home and family life, mealtimes and their resulting upsetting interactions became one of the biggest sources of anxiety, distress, and conflict, and as outlined by Eisler (2005), often dominated life homelife, with mealtimes sometimes “lasting for hours”. Many studies echoed this finding (E.g. Perkins et al., 2004; Fox et al., 2017; Schmidt & Treasure, 2006; Jaffa et al., 2002; White et al., 2020), with one participant in Cottee-Lane and colleagues’ (2004) study saying: “I’d shout, everybody else would cry”. Hannah White and colleagues (2020) conducted a qualitative study solely focussed on how mothers experienced mealtimes when caring for their anorexic child. Through semi-structured interviews with nine mothers, and the use of IPA, three themes were produced that further highlighted the difficult nature of mealtimes for the whole family, showing mothers losing confidence in their ability to care due to increased mealtime uncertainty. Transferability of these findings may be limited however, as the sample was self-selected, which could suggest that motivation to take part meant that mealtimes were experienced differently to those that did not want to engage. Purposive samples are widespread in qualitative literature however, therefore self-selection is difficult to avoid. Although a benefit to IPA, the sample was also small.

Unsurprisingly, relationships within the family became strained (e.g. Dimitropoulos et al., 2009; Fox et al., 2017). Svensson et al. (2013), a qualitative study exploring the parental carer experience, supported this further, finding evidence of strain in both spousal relationships (often due to periods of separation), and sibling relationships (often due to a reduction in attention and general frustration). A phenomenological hermeneutical method was utilised to analyse the data. The sample was comprised of an almost even number of mothers and fathers, a strength, as literary data of fathers is scarce. Additional literature described parental conflict and a breakdown or change in the relationship between the child and the primary caregiver (PC), often because of the challenging behaviour that presents alongside AN (Espina et al., 2003; Lask, 2000; Gilbert et al., 2000; Carpinelli et al., 2022), which could include severe mood swings, selfishness, deviousness, and aggression (Treasure et al., 2001).

1.3.2 Emotional impact

The severe emotional toll taken on the caregiver was reported across the majority of the literature, with parents seemingly experiencing feelings of worry, anger, sadness, distress, frustration, and confusion, among others (E.g. Blondin et al., 2019; Fox et al., 2017; Kyriacou et al., 2008). Parental feelings of self-blame and guilt were also identified, reportedly stemming from reflecting on, and interpreting their own actions, such as questioning their parenting, not being able to halt the progression of the illness, and holding onto the notion that they "ought to have seen it coming" (Fox et al., 2017; Whitney et al., 2005). Hoskins & Lam (2002) too heard mothers say similar things, including "I feel I have let her down as a mother.. I think she blames me, .. maybe she is right", "I should have seen it coming", and "I felt like it was my fault", clearly depicting the anguish and self-reproach they were feeling. This study was investigating how the mothers' sense of self and understandings of mothering had been impacted by the role, using discursive psychology and constructivist theory. The open-ended interview style utilised, facilitated the generation of rich data. However, the fatherly experience was not represented (common in the literature), and the sample of mothers was smaller than average, at three.

The review further found that unsuccessful efforts to aid or influence their child's behaviour, led to feelings of frustration and powerlessness in the parent (Lask & Bryant-Waugh, 1993; Tierney, 2005). Consequently, many parents experienced increased uncertainty about their child's recovery, and found themselves faced with the real possibility of losing them to AN (Fox et al., 2017; Cottee-Lane, 2004; Carpinelli et al., 2002). Interestingly, Sharkey-Orgnero, (1999) learned through qualitative exploration using grounded theory, that for some mothers, their ability to cope effectively with their daughter's AN was compromised due to these high stakes. It is perhaps important to also hold in mind that a caregiver's emotional state may have a detrimental effect on their child's AN symptoms and recovery (Kyriacou et al., 2008; Duclos et al., 2023).

1.3.3 Social impact

An aspect of the carer's role also evident through the literature, was the impact it had socially, with studies showing how parents were often required to sacrifice activities that were occupational, leisurely, or social in nature, to meet the practical and emotional demands that the role of carer imparts (Nilsson et al., 2012; Fox et al., 2017; Sepulveda et al., 2008). These sacrifices were not limited to short-term adjustments, but were often experienced over long periods of time, creating an ongoing, persistent disruption to carer's lives, and refer to activities both in and out of the familial home (Nilsson et al., 2012). Additional insight was provided by Beale et al (2005), who reported parents experiencing isolation from friends and family, something echoed by Loftfjell et al (2020), particularly at the height of their child's illness. The findings described how this was due to both external exclusion, often because of negative attitudes or insufficient understanding, and conscious isolation so as to focus on the role at hand, in a bid to manage the situation as best as possible. This was an Australian qualitative study, that administered in-depth interviews to 22 parents (19 mothers, 3 fathers), and used Q.S.R.NUD.IST to analyse the data. Like many identified in the review, this study used a small, self-selected sample. However its findings are corroborated by several other studies (El-Sayad, 1998; Loukissa, 1995; Fox et al., 2017; Svensson et al., 2013).

The aforementioned lack of understanding from friends or family was widely discussed in the research, and identified as a significant driver of isolation. After seeking support from others only to be met with various unhelpful questions, comments or opinions, parents reportedly reached the realisation that coping alone was likely their only option (e.g. Highet et al., 2005; Hillege et al., 2006; Whitney et al., 2023). Experiences of insufficient understanding extended beyond close relationships, with past research also uncovering experiences of insufficient understanding in the context of communities (Highet et al., 2005; Eisler, 2009) which, alongside the anxiety and shame resulting from perceived social stigmatisation (Whitney et al., 2018), fostered a "keep it in the family" attitude, thus catalysing social isolation (Whitney et al., 2023; Fox et al., 2017). In Cottee-Lane et al's (2004) study, four couples and three single mothers took part; the latter reported that trying to find support from others had been particularly difficult, noting feelings of abandonment from friends and community networks. Moreover, studies showed that the social isolation experienced by carers during the caregiving period, often had enduring effects, extending far beyond their child's recovery (Fox et al., 2017), seeing some parents reporting significant difficulties when attempting to re-establish their social connections and re-integrate into networks and communities, all with varying success (Geller et al., 2024).

1.3.4 Experience with health professionals and services

How parents experienced working with and/or alongside health professionals arose in the literature, with both negative and positive experiences reported. Upon literary synthesisation, it appeared that for most, the initial experience had been negative for the most part (E.g. Fox et al., 2017; Whitney et al., 2023), with multiple reports of lengthy processes, wait times, and delayed treatment access, and a satisfactory level of support only reported in reference to FBT or specialists (E.g. Krautter & Lock, 2004; Beumont-Schrader et al., 1993). Parents shared their disappointment regarding being kept in the dark, excluded from their child's treatment, and reported a general lack of access to information (Winn et al., 2004; McMaster et al., 2004). Tierney (2005) explored this further, by conducting a qualitative study in the UK that set out to interview the parents of anorexic adolescents about their experience of treatment. Two mothers and six sets of heterosexual parents were interviewed, with the data coded and inputted into Atlas-Ti for theme clustering. The findings showed lack of empathy, misdiagnoses and stigmatisation were all experienced upon initial access to treatment, but that views and experiences surrounding family therapy were largely positive. The absence of communication arose also, leaving parents feeling isolated and unclear about their child's progress. This last finding was supported by multiple studies reporting parents experiencing their initial concerns as being disregarded, and being made to feel incompetent (Nicholls & Magagna, 1997; Haigh & Treasure, 2003; Ross & Hardy, 1997; Kopec-Schrader et al., 1993; Coelho et al., 2021).

Further findings from Fox et al (2019), and Surgenor et al (2000), found that when interacting with health professionals the participating caregivers often felt misunderstood, scrutinised, and blamed, and that the importance of providing families and parents with ED education was often underestimated. Additionally, it was discovered that when seeking advice or support from their doctor or GP, over 50 percent of caregivers reported unmet needs (Haigh & Treasure, 2003). Many researchers shared their belief that if the integral role that parents play in their child's recovery was recognised by professionals, the parent experience, and likely the care provided, would improve.[7]

1.3.5 Positive impact

Despite the abundance of negative experiences shared, a minority group emerged describing positive experiences, with themes including increased marital and familial strength, improved familial communication, and personal growth (Highet et al., 2005; Ott, 2020). For example, Perkins et al (2004) found that despite the challenges faced at home, for some, an opportunity to grow and come together as a more closely knit unit was grasped, leading to the functioning of the child/sibling, and parent/child relationships all improving. Moreover, Treasure et al (2001) stated

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[7] It is worth noting however that parental experiences of accessing care privately do not seem to have been explored, thus identifying a potential gap in the literature, that could yield interesting and valuable results.

that some parents believed their relationship with their child to be better than ever, and that despite the complexities and at times distressing nature of their experiences, there existed an undertone of love, support and acceptance throughout the interviews. A qualitative study looking to explore the experience of ten mothers caring for their anorexic sons, lends further support (Whitney et al., 2023). Six mothers reported post traumatic growth, suggesting that the carer role, and their son's AN, helped them develop a changed outlook on life, increased empathy, gratitude, and an improvement in reflection and self-awareness. Four mothers saw having to work as a team to make treatment and parenting decisions as having strengthened their marriage (six reported marital stress however), and another four described the unification of their families, and a closer mother/son relationship. Consensual qualitative research was used. This study provides rich data, contributing to the small pool of research that includes sons. There are however a few limitations to consider, including not being able to draw on fatherly experiences.

1.4 How having or previously having had an ED may shape the parental experience.

To fully address the question guiding the literature search, with its emphasis on parent carers with a history of AN, a second literature search was carried out. Again, the four electronic databases PsychINFO, Google Scholar, and PubMed were searched, to ascertain how the parental experience may be shaped by having, or previously having had, an ED. This time terms including 'parents with eating disorders', 'lived experience of anorexic mothers', 'being a parent with an ED/anorexia', 'recovered anorexic parent/mother', 'anorexic mothers', 'anorexic parents and children', were used in the search. The broader remit of the search, which included EDs and no longer solely AN, was dictated by the researcher's awareness that there would be less literature on this subject. Given the prevalence of EDs among adolescents they have been the prime focus of research in the field, and adults with anorexia tend to be under-researched (Wright & Hacking, 2012). It seemed important not to miss any accounts of parenting with AN, just because they fell under the broader title of EDs. This time the search yielded 109 references. 42 were retained and used here.

Quickly into the search, it became apparent that parents living with anorexia, and adults more generally, were indeed woefully under-represented. Of the research that does exist much was old, using a quantitative methodology, focusing on understanding the consequences of EDs on pregnancy and infancy, such as low birth weight (E.g. Micali et al., 2007; Waugh & Bulik 1999). It appears that few studies have explored parental experiences past this early stage and considered how having, or previously having had an ED may impact the ongoing parent/child relationship, or the experience of parenting (as a mother or father). Furthermore, some existing literature appears tinged with 'mother-blaming', whether explicitly or implicitly (E.g. & Fisher, 2000; Woodside & Shekter-Wolfson, 1990). To the researcher's knowledge, the only qualitative studies that have investigated the parental experience after previously or currently having an ED specifically, are by Stitt & Reupert (2014), Fitzpatrick et al (2023), and Chapman et al (2023). The former two used (IPA) to approach their data, while Chapman and colleagues used Thematic Analysis.

Stitt & Reupert (2014) recruited nine mothers in Australia (despite advertising to men too), with a mean age of 36.1, who had children ranging in age from five months to 27 years. Participants had formal diagnoses of either AN, BN, or EDNOS, diagnosed both before and during parenting, and were recruited through community channels. Although a homogenous sample, a limitation is the lack of diversity regarding geographic representation, as the findings may not represent mothers in different countries or cultural contexts. Fitzpatrick et al's 2023 study aimed to explore the lived experiences of mothers in the UK, with experience of diagnosed AN specifically. Six mothers above the age of 18, who had AN whilst raising their children but considered themselves 'recovered', were recruited. It is worth noting that all participants were heterosexual and white, limiting the transferability of the research findings to those from different backgrounds. The study also explores the mother having AN whilst raising her children only, therefore providing no insight into parenting in recovery. The final qualitative study, by Chapman and colleagues (2023), had a larger sample size, recruiting 18 mothers between 30 and 48 years of age in the UK, USA, and Australia (again, no man came forward). Children's ages across the male and female sample were between two and 17. Participants presented with a range of EDs, which they experienced both before and during parenting. Although the sample was larger and covered three continents, like the previous study, other ethnic backgrounds were not represented. Like for Stitt & Reupert, co-morbidities were present for many, enhancing the possibility that some experiences may have borne more relation to those symptoms, rather than their EDs.

None of the three studies capture the experience of fathers experiencing an ED. Despite their limitations however, all provide rich, in-depth insights into the lived experience of a phenomenon that is wholly underexplored, therefore contributing to the small body of research focussing on mothers who have had, or have, AN or another ED. Emergent themes from across the studies will be outlined and critically discussed below, alongside the results from relevant quantitative studies.

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1.4.1 Impacts on food-related parenting

All three studies highlighted how food-related parenting appeared to be impacted by the mother's

ED, showing incidences of increased control and mealtime rigidity, and underfeeding, something also described in other qualitative findings (Bryant-Waugh et al., 2007; Stapleton et al., 2008; Sadeh-Sharvit et al., 2015; Ferreira et al., 2021). Numerous reports supported this notion, with Stein & Fairburn (1989), a study with both quantitative and qualitative components, suggesting that mothers with severe BN may restrict the amount of food at home, and others such as Evans & le Grange (1995), and Woodside & Shekter-Wolfson (1990), both primarily quantitative studies focussing on parents with AN and BN, finding they may also not eat in front of, or cook for their children. Several studies have concluded that as a result, the children of mothers with EDs fail to thrive (e.g. Stein & Fairburn, 1989; Vignalou, 2006; Brinch et al., 1988). A quantitative study using analyses of variance to compare the influence of mothers with and without past and present EDs (AN, BN, BED) also reported evidence suggesting behaviour towards children was different, particularly in early childhood (Agras et al., 1999). This included feeding schedules that were less organised, and using food for non-nutritional purposes, such as calming their child down, or as a reward. Participants had both sons and daughters, a strength relatively uncommon in this area of research; however, for a quantitative study the sample was small, particularly after dividing by child gender, making results difficult to interpret based on the differing types of ED, or the effects of past and present. Like many, this study did not follow the children as they grew older, and it is unclear how they may have been impacted longer term. Non-nutritional feeding has been reported elsewhere, with Braden et al (2014) finding that offering food to soothe negative emotions was present within mothers with BED. Past longitudinal studies have also found that babies developed behavioural and emotional problems due to maladaptive relationships around feeding, when one or both parents have BED (E.g. Camino et al., 2016).

Similar findings have been generated by Birch & Davison (2001), regarding parents with difficulties around eating control, who were found to utilise a controlled way of feeding with their children to prevent them from becoming overweight. Chapman et al (2023), Fitzpatrick et al (2023), and Smitt & Reupert (2014), saw participants communicate their concerns regarding their ability to parent and feed their children sufficiently, and their fears that they would pass on their ED to their children, bearing responsibility for eventual unhealthy attitudes to body size and shape. Echoing this, Bryant-Waugh et al. (2007) found mothers to be fearful of this risk, as did Russell et al (1998), and Franzen & Gerlinghoff, (1997).[8] The literature further suggests that mothers with EDs also display an over-concern about their child's shape and weight (Reba-Harrelson et al., 2010; Stein &

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[8] These fears are not unfounded: according to Stein et al (2006), dysfunctional eating behaviour and attitudes in children are more likely to develop the more time they are exposed to the same in their parents, thus internalising parents' fears, and the subsequent use of food as a 'preventative' tool as described by Birch & Davison in 2001 (see also Russell et al., 1998; Franzen & Gerlinghoff, 1997).

Fairburn, 1998). For example, mothers with BN have been seen to not want their child, particularly those over two, to overeat (Russsell et al., 1998), with others attempting to help their young children lose weight (Agras et al., 1999). Lacey & Smith's (1987) study supported this, observing that 15% of the 20 bulimic mothers that participated had tried "slimming their babies down" by the time they turned one. These studies were quantitative however, thus removing the opportunity to hear, and understand how the mothers experienced this. Moreover, they focussed only on mothers with BN, leaving those with AN unexplored. Interestingly, Agras et al. (1999) found that much greater concern was expressed in relation to the participants' daughters' weight, in comparison to their sons'; and of the six children in Stein & Fairburn's 1989 study, three were found to have developed an ED of some sort as a result. This aligns with Brun and colleagues call to address, through research, how we can "help mothers end the intergenerational transmission of body dissatisfaction and disordered eating to daughters" (Brun et al., 202, p.2).

1.4.2 Treading the tightrope between parenthood and an eating disorder

Something evident across the focal qualitative studies and others, was that many mothers found trying to manage the demands of both parenting and the ED challenging, with a meta-ethnographic study exploring the experience of women with EDs in the perinatal period, finding it to cause anxiety and stress (Fogarty et al., 2018). Participants in Tierney and colleagues' 2011 study echoed this, describing difficulties in maintaining a balance that allowed them to respond to the needs of their ED, whilst ensuring their child's needs came first. This was a qualitative study exploring motherhood and EDs, that interviewed eight mothers with a range of EDs. Whilst this study produced several supporting findings, therefore positively contributing to the small pool of literature, it concentrated solely on pregnancy and the first two years of parenthood, with a particular focus on how the mothers' ED manifested during that time, not how the ongoing parental experience was shaped.

Developing this, Chapman et al (2023) found that parenting obligations would sometimes interfere with or aggravate the demands of the ED, causing a need to schedule ED behaviours in order to satisfy them. Findings also suggest that as a result many mothers felt undeserving, as when you are a mother "other people come first" (Fitzpatrick et al., 2023. This internalised idea of the 'selfless-mother' (Hays, 1996), and the internal conflict that resulted was widespread throughout the literature, with several studies demonstrating how this made self-compassion difficult, causing feelings of guilt, pressure to present and behave as the 'perfect mother', and an increased risk of stress, reduced self-efficacy, and anxiety (e.g. Henderson et al., 2016; Fitzpatrick et al., 2023;

Rortveit, 2010). Again, feelings of guilt were present through much of the literature. However the causes and experience of this guilt, were also seen to be slightly different at times. Many spoke of the judgements experienced from others because they were either parenting or pregnant with an ED, often coming from family members and health professionals, and how these exacerbated feelings of guilt and shame, as well as regret and sadness (e.g. Fitzpatrick et al., 2023; Tuval-Mashiach, 2013; Tierney et al., 2011; Chapman et al., 2023). Rørtveit et al (2010) conducted an entire qualitative study exploring ED mothers' understanding of their guilt and shame. However a lack of specificity regarding what EDs the mothers had precluded any exploration of whether and how experiences of guilt and shame could vary, for instance between BN and AN. Guilt was also presented as an overarching theme encompassing any and all experiences, again at the risk of losing the meaningful and idiosyncratic elements of participants' experience. The way Stitt & Reupert (2014) presented similar findings independent of guilt, also seemed less pathologizing.

Research showed the internal conflict experienced not only caused guilt, but also a lack of emotional and psychological presence (Claydon et al., 2018; Stapleton et al., 2008; Tierney, 2011), particularly due to ED-related preoccupation, with a participant in Stitt & Reupert's study (2014), saying "my head's too full". Mothers reported that this emotional absence caused worry surrounding not being a good parent, and that their children were missing out (e.g. Chapman et al., 2023; Stitt & Reupert, 2014), with some also developing a more lax parenting style, enabling them to focus on the rules imparted by their ED that they were consumed by (Ackerson, 2003). Conversely, Montgomery et al (2006) found that mothers with MH difficulties outside of EDs, were able to always prioritise their child's needs over their own, despite any detrimental effects on their own recovery. This may add theoretical weight to the evolving theory that ED and NED parent/child relationships are different, most likely due to the controlling nature of EDs themselves, perhaps warranting further exploration.

1.4.3 Impact on ED and recovery

How mothers experienced their ED and any changes therein, particularly as new mothers, was a prominent discussion topic throughout the literature. When reporting on parent/child support groups for mothers with AN and BN, Franzen and Gerlinghoff (1997) found that despite the many challenges that accompany parenting with an ED, the fear of impacting their child negatively because of their ED catalysed the treatment seeking process. This is supported by several additional studies, that demonstrate how becoming a parent and having children can be a motivating factor (Chapman et al., 2023; Stitt & Reupert, 2014; Sadeh-Sharvit, 2015), with many mothers attributing their recovery to wanting to be a better parent, fearing for their child's health, whilst also seeing their children as integral to their initial recovery and continued motivation (e.g. Stapleton et al., 2008; Papadopoulos et al., 2013). This is supported by quantitative research conducted by Soest & Wichstrom (2008), who found that eating difficulties and body image can be positively affected by motherhood. However, it is worth noting that whilst all of the aforementioned studies provide valuable insight into the catalyst that motherhood can be for recovery, little knowledge is available about fatherhood and EDs.

Moreover, for some, becoming a mother resulted in a deterioration of ED symptoms (Chapman et al., 2023), with Arnold et al (2019) finding that mothers who have a history of AN but were recovered at the time of having a child, experienced a relapse. Some argue that seeking and engaging in treatment as a response to external motivation (i.e. their child), is not always evocative of longer-term recovery (Federici & Kaplan, 2008), something evidenced by a participant in the latter, phenomenological study, when a mother relapsed once her children moved out, highlighting the need for internal motivation when it comes to ED recovery. Multiple studies have also identified how parents with AN or BN may feel triggered by the role in ways that are unrelated to eating or food. These included family conflicts, their child's shape and weight, having to hide their disordered behaviours, and usual daily stresses of parenting, with these also being intensified because of having an ED (Chapman et al., 2023; Franzen & Gerlinghoff, 1997; Hoffman et al., 2015; de Barse et al., 2015).

1.5 Anorexic daughters and anorexic mothers

Much of the literature discussed thus far has highlighted what appears to be a significantly increased likelihood of developing an ED if you are a child of a parent with an ED. These findings, and the continually emerging literature surrounding the influence of genetics, prompted a final search to review what is understood about the experience of parenting a child with an ED, when you have, or have had an ED too. The same databases were searched using terminology including "experiences of parents with EDs parenting children with EDs", "parents and children with EDs", "anorexic daughters and mothers", "intergenerational EDs", "recovered anorexic parents" and further combinations of words such as 'anorexia', 'eating disorders', 'families', 'parent/child anorexia'. Despite a thorough narrative search, no scholarly articles of relevance were found. A search of possible grey literature using Google only yielded a couple of articles written from the child's point of view as an adult, describing how it felt to grow up around a mother with an AN, and the subsequent development of, and recovery from their own AN, whilst their mother remained unwell (Taylor, 2023; Green, 2023). Again, nothing specific to the exact area of interest was discovered, highlighting a substantial gap in the literature, and a need for further exploration.

1.6 Research question and aims

In order to address this gap, the present study sought to explore the following question:

> "What is the lived experience of recovered anorexic mothers, caring for their anorexic daughters?"

The hope was that this study would advance our knowledge of the carer experience in a way that has not been done before, and that exploring the nuanced and likely complex nature of mothers' experiences, and the interplay between caring for a child with AN and their own personal history, would lead to a better understanding of the challenges faced and support needed. It was also hoped that the interview, and the research in its entirety, would be of value to the mothers who agreed to participate, by providing an opportunity to share their stories and experiences in a way that felt empowering, validating, and hopeful.

1.6.1 Why mothers and daughters?

As previously noted, AN is also seen in males (Gorrel & Murray, 2019), however, this research focused on mothers and daughters only. Partly, this is because it sought to build on the existing literature, to therefore see how contending with one's own AN might affect what we already know about mothers' experiences. Had fathers or sons been considered, the paucity of work on fathers' experiences, and on caring for sons with AN specifically, would have made that more difficult. Additionally, including both fathers and mothers, or daughters and sons, might also have presented methodological challenges, as the methodology chosen, IPA, requires the use of a homogeneous sample (more on this in the next chapter).

1.6.2 Why recovered?

Evident from the research question, the study is aiming to focus on 'recovered' anorexic mothers. Although exploring the experience of mothers caring for their daughters with AN whilst actively dealing with AN would likely generate valuable findings, this is not the experience that this particular study was looking to understand. Research has indicated that recovery can alter one's perception of EDs, and subsequently (and unconsciously) their approach to caregiving, for example, fostering greater empathy, or conversely, heightened vigilance and control (LaMarre et al., 2024). Using this criterion therefore allowed for a specific, targeted investigation into how past experiences of AN may have impacted the caregiving process, ensuring greater clarity in findings. To manage risk during interview, it was also deemed important that mothers were recovered for a significant amount of time, and felt a sense of distance from their own AN.

It is important to note that the term ‘recovery’, or ‘recovered’ within AN, is not black and white, includes both physical and psychological variables, and does not mean or look the same for every individual (Murray et al., 2018). The inclusion and selection criteria used for both mother and daughter will be outlined in the following chapter.

1.7 Relevance to Counselling Psychology

The field of Counselling Psychology (CP) is focussed on existing within the wider “world of helping” (Woolfe, 2016), paying particular attention to the formulation and understanding of the client experience and worldview (Jones Nielson & Nicholas, 2016). It prioritises the human experience, ensuring that it is at the heart of clinical, ethical, and research endeavours (Cooper, 2009), and is seen from a holistic perspective (Frankland & Walsh, 2005). The central focus on, and exploration of the lived experiences within this study therefore aligns with the ethos of CP, as does the study’s commitment to ensuring awareness of the influence of social context, and the respect of first-person narratives (British Psychological Society [BPS], Division of Counselling Psychology, 2006). For example, ensuring the consideration of sociocultural influences, such as societal attitudes towards MH and caregiving, ED stigma, and the expectations placed on mothers within different cultural frameworks. These factors can profoundly shape the caregiving experience and the therapeutic needs of both the mother and the child (Highet et al., 2005). It was hoped that through conducting a practical research study that contributes to our knowledge and deeper comprehension of this phenomenon, by exploring the multifaceted and intricate realities that the mothers experience, the CP values could be put “into action” (Cooper, 2009). As mentioned previously, it was also hoped that participants would feel empowered from taking part in this study, which is something CP strives to achieve, alongside the actualisation of potential and the facilitation of growth (Douglas et al., 2016).

An aim of the study is to generate information of importance and value that will be of use to CPs, particularly those working with EDs, and to other MH professionals. It is hoped that the production of such knowledge will help to shed light on the nuanced nature of the experiences of carers, highlighting any challenges faced and need for support. This will, in turn, help to better tailor therapeutic interventions, improve the support available to both the mother and their families, and ensure that the integral role that a mother plays in their child's process of recovery continues to be acknowledged (Highet et al., 2005), to ensure both their safety, and that of their child.

1.8 Reflexivity and Relationship to Research

The following aims to demonstrate my close connection to the research and its development. According to Finlay (2003), for researchers, reflexivity is the process of reflecting on interpretations relating to both the studied phenomenon and their own experiences, continually, in an effort to move past preconceptions. A reflexive researcher will therefore be able to separate identified experiences from the specific phenomenon, whilst paying attention to how the course of the study is dictated or affected by his or her interpretations. Being a trainee CP means that reflexivity has been at the heart of my work and training throughout, helping me to make sense of my thoughts, assumptions, and relationship with the world and those around me, something I have discovered to be invaluable.

According to Willig (2013), there are two fundamental types of reflexivity: personal reflexivity, looking at how my life experiences, beliefs, and values may shape or impact the research; and epistemological reflexivity, which encourages reflection surrounding the researcher's theoretical assumptions, and how findings may be shaped by these. The following is regarding the former.

The adoption of a reflexive stance has seen me engage in self-reflection from the outset when exploring and deciding on an area of research, using a personal diary throughout. I have had an interest in EDs, and working with them, for over a decade, and something that has perhaps fed, or even sparked that interest, is personal experience. During adolescence, I experienced some challenges surrounding food restriction, and loss of food control. Although it did not become severe enough to require hospitalisation or long-term care, I needed support from a psychologist. This experience gave me first-hand insight into the all-consuming, all-controlling nature of an ED, notably the concealing, deceitful, and unhealthy behaviours that are often in accompaniment (Vandereycken & Van Humbeeck, 2008), and the subsequent carer desperation and interpersonal conflicts. I believe that my initial desire to explore the carer experience stemmed from the accumulation of reading the literature, hearing accounts from others, and my own experience, and crystallised upon discovering a significant gap in the literature. However I was mindful that as a result, I might naturally possess and bring presumptions with me into the research. The way I monitored my feelings, reactions and emergent interpretations is further discussed in the next chapter.

2 METHODOLOGY

2.1 Introduction

After reiterating the research question and aims, this chapter will present the project’s ontological and epistemological position and provide a justification for the choice of Interpretative Phenomenological Analysis (IPA) as its methodology. A detailed description of the study’s design and procedures will then be given, followed by an exploration of some of the ethical challenges faced along the way. A reflexivity section concludes.

2.2 Research Question

What is the lived experience of recovered anorexic mothers, caring for their anorexic daughters?

2.3 Rationale for a Qualitative and Phenomenological Approach

It is important that the research methods chosen for a research study are appropriate and oriented to the research question being asked, and of good personal fit with the researcher (Willig, 2013). The research paradigms, qualitative and quantitative, hold differing assumptions regarding the human experience and the nature of knowledge and understanding (Bhati et al., 2014). Quantitative research seeks a measurable objective truth and is hypothetico-deductive in nature, looking to quantify and measure data, test hypotheses, and identify correlational or causal relationships between manipulated empirical variables. Qualitative research however seeks to facilitate the exploration of behaviours, cognitions, and sensations identified through discourse (Tresca, 2018). It welcomes the richness of the individual experience (Austin & Sutton, 2014), and honours the participant’s voice. As this study is centred around the exploration of the idiosyncratic experience of individuals, a qualitative paradigm was deemed a suitable fit. IPA therefore also aligns closely with the aims of the study. As a qualitative approach, it focuses on exploring how individuals make sense of their personal and social worlds (Smith et al., 2009). It provides a rigorous framework that enables the in-depth exploration of these subjective accounts, whilst acknowledging context and the complexity of these experiences (Smith et al., 2009), and is therefore particularly well-suited to addressing the research question, which seeks to understand the unique caregiving experiences of recovered anorexic mothers caring for their anorexic daughters.

A phenomenological approach was further used within the qualitative paradigm. Phenomenology also rejects the quantitative positivist stance, rather focussing on comprehending how humans make sense of their social and personal worlds to better understand the human condition and its complexities (Willig, 2013), thus getting as near as possible to their lived experience. Despite misconceptions that an interpretative phenomenological approach is purely descriptive (Larkin et al., 2006), the approach aims to improve knowledge around the wider cultural, psychological, and social context of an experience (Willig, 2013).

Consideration was also given to the notion that one's own axiology can influence methodological choices (Creswell et al., 2007), and the qualitative paradigm aligns with the beliefs and values that drew me to Counselling Psychology (CP) initially, and with my desire to explore the subjective human experience.

2.4 Ontological and Epistemological Position

Philosophical assumptions tend to be "unacknowledged and implicit" (Willig, 2013), therefore it is important for all researchers at the beginning of a project to reflect on their perception of reality and knowledge, paying attention to their ontological and epistemological positions, as the way reality is perceived defines the way in which knowledge about it is obtained, thus guiding the methodological investigation (Guba & Lincoln, 1994). Ontology is concerned with the nature of the world, what exists, and what there is to know, whereas epistemology wants to know how we can know this (Maxwell, 2012), with a focus on the researcher and participant relationship (Ponterotto, 2005).

2.4.1 *Ontological Stance*

Ontology is on a spectrum, on which there are a range of perspectives and positions, with the extremes being realist and relativist (Willig, 2012). A researcher with a realist ontological stance would assume that an objective reality exists independent of human perception, interpretation, and beliefs (Maxwell, 2012), a reality with phenomena that are verifiable, beyond subjective interpretations (Willig, 2012). Moreover, he or she would further posit that beneath observable phenomena lie causal mechanisms that give rise to events and can be understood and investigated (Gorski, 2013; Zhang, 2022). A relativist perspective, however, suggests that there are multiple realities, that are shaped and mediated culturally, historically and socially through language (Guba, 1992), and rejects the concept of 'knowledge' or 'truth', because no individual interpretation can be claimed to be true or untrue across differing cultural or social frameworks (Forsberg, 1992). It emphasises the inherently subjective, context-dependent, and culturally contingent nature of reality, and challenges the notion of a singular, objective truth.

The ontological stance that this study subscribes to is one that occupies a position on the spectrum between these two extremes – critical realism. Credited originally to Roy Bhaskar (Bhaskar, 2008), critical realism accepts that there might be numerous versions or accounts of a phenomenon, and that no human being can have certain or 'objective' knowledge about the world (Maxwell, 2012). It holds the assumption that reality is multiply determined, and stratified into the following domains (Bhaskar, 1975) or 'iceberg' structure (Fletcher, 2017): the 'empirical' (observable or tangible reality), the 'actual' (hidden layers of reality, e.g. underlying mechanisms), and the 'real' (transcendent, enduring reality underlying/encompassing all observable phenomena). To explain further, existing in the world are 'real' things, yet there is no assurance that they are known about or sensed, and from these real things interacting, comes the emergence of 'actual' events. The associated 'empirical' data then guides our action and informs our sense-making through human interpretation (Bhaskar, 2017).

Critical realism posits that reality exists independently of theories, context and perceptions (Phillips, 1987), that it can be known and accessed. It also considers that due to perceptual constraints that limit our ability to make sense of the world, human awareness merely skims the surface of said external reality, thus capturing only a superficial impression of its depth and vastness. It also posits that people perceive unique elements of the same reality, creating variability in experience, although some interpretations inevitably reflect the true nature of a phenomenon more closely than others (Bhaskar, 2017). The approach has therefore been characterised as a "marriage of epistemological relativism and ontological realism" (Vincent & O'Mahoney, 2018, p. 201). Whilst I accept that a shared, external reality exists, I believe it cannot ever be completely understood. I assume therefore that each participant's reality is true, once it has been processed and made sense of through their interpersonal interactions, unique perceptual, cognitive and emotional systems, and through dialogic construction.

2.4.2 *Epistemological Standpoint*

Epistemology is concerned with the theory of knowledge, and the study of its origins, nature, and scope (Borchert, 1967). It seeks to understand what knowledge is, and how it is acquired, with Laverty (2003, p.12) describing it as "the nature of the relationship between the knower and what can be known". Phenomenology, a philosophical discipline that concerns itself with the structure of experience (Crotty, 1996), examines the life world or lived experience (van Manen, 1997), and focuses on how these are individually experienced, rather than seeing reality or the world as something distinct from a person (Valle et al., 1989). Phenomenologists seek to discover meanings as they are experienced in daily life, with Martin Heidegger stating in his book ‘Being and Time’ (1962, p. 38), that we ought to be focussing on the way in which we live in “our average everydayness”. It asks the question “what is this experience like?”, wanting to understand experiences from the point of view of the first person (Pietersma, 2000).

A researcher adopting a phenomenological epistemological standpoint therefore aims to develop a greater insight into a phenomenon from within, enhancing the quality of our understanding of the experience itself (Willig, 2013). This is a befitting position for this study, as it seeks to explore the subjective experience of previously anorexic mothers having to care for their anorexic daughter. Furthermore, it is in line with my critical realist ontology which supports the phenomenological notion that one’s ‘reality’ is a construction (Willig, 2013). As explained by Laverty (2003), Heidegger asserted that every interaction with a phenomenon necessitates an interpretation shaped by a person’s historicality and background, as ‘to be human is to interpret’. Here an interpretative perspective will be held, ensuring participants’ descriptions of experience are not taken at face value but are interpreted empathically, to enable further sense-making and insight (Willig, 2013). As my interpretations will inevitably be influenced by what I have learned from existing literature about the caregiver role through my research into the area, my clinical experience working with EDs, and my own circumstances, the need for, and value in reflexivity throughout is emphasised. This approach also resonates with the principles of Counselling Psychology, namely seeking to respect and understand subjective accounts and narratives. CP integrates therapeutic practice and research, creating a dynamic interplay where clinical work informs research and vice versa, deepening therapeutic understanding (Cooper, 2009). This aligns with the study’s aim to explore the lived experience, whilst hopefully offering insights that will enhance therapeutic practices for those affected by AN or EDs more generally. This approach is also consistent with my own perspective as a researcher.

2.5 Research methodology

2.5.1 Interpretative Phenomenological Analysis

IPA was designed primarily for psychological research and aims to gain insight into the psychological world of participants (Willig, 2013), helping to make sense of, and give a voice to, their discoveries and subjective experiences (Larkin et al., 2006) - something that is facilitated by a researcher’s interpretation.

Drawing on phenomenology, hermeneutics, and idiography (Pitkiewicz & Smith, 2014), IPA aims to identify the qualitative and experiential aspects of human interaction with the world, in a bid to better understand the individual lived experience (Willig, 2013). As stated previously, phenomenology examines an individual's life world (Smith & Osborn, 2003). It is rooted in the philosophy of Edmund Husserl, who stated that the main aim of phenomenology is to explore how one might come to know and understand their individual experience of a phenomenon, and that for this to happen, and to see the essential qualities of this (Smith et al., 2009), one must engage with these individual experiences rigorously and deeply (Husserl, 1970). Husserl suggested that upon entering the research process, we adopt a 'phenomenological attitude', stepping outside of one's 'natural attitude', without a predetermined hypothesis.

Husserlian concepts such as 'reduction' and 'bracketing'[9] inform the methods of IPA (Smith et al., 2009). However, IPA draws more heavily upon hermeneutic phenomenology, and the work of Husserl's successors, perhaps most significantly Martin Heidegger, who queried any knowledge that did not exist within an interpretative framework. He defined phenomenology etymologically, and found the word to be composed of phenomenon and logos (Heidegger, 1962), with the former translated as 'appear' or 'show', and therefore primarily perceptual, and the latter as judgement, reason or discourse, thus primarily analytical. Although phenomena may initially 'appear' to show themselves, "…analytical thinking required by the logos aspect then helps us to facilitate… this showing" (Smith et al., 2022, p. 20). This approach to phenomenology is readily adopted in IPA, therefore tying it to the perspective of hermeneutics. Furthermore, as argued by Heidegger, it is likely that our assumptions and preconceptions will form the foundation of said interpretative element (1962), some of which may precede, or follow, our encounter with a phenomenon. Nevertheless, through the (cautious) use of preconceptions, an analyst can offer a perspective on the research text that the author cannot, therefore adding value to the process (Schleiermacher, 1998).

Being an idiographic methodology, IPA concerns itself with the particular, using detailed examination to achieve analytical depth. The approach posits that while the researcher cannot enter the participant's world fully, she can draw out previously hidden details by considering contextual information and adopting a psychological viewpoint to make sense of participants' sense-making (Ashworth, 2003). According to the idea of the double hermeneutic, the research exercise follows a two-stage, dynamic process that sees the researcher adopt an active role, calling on their own conceptions, so as to be able to interpret and make sense of how a participant interprets their own

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[9] Reduction: returning to the experiential content. Bracketing: a technique used to put aside any prior understanding or knowledge, to ensure complete, uninfluenced focus on the phenomenological experience of the participant.

world and lived experience (Smith & Osborn, 2003). Often, only a small number of participants or cases are used, but these are focussed on and explored more extensively, to reflect the richness and complexity of individual descriptions. Analysis typically begins with a close and detailed examination of individual accounts, followed by a tentative evaluation of the differences and similarities between them. The in-depth exploration of the interview data can then lead to the discovery of emergent themes, and the identification of differing or shared experiences (Smith et al., 2009).

IPA thus assumes that there is no singular reality that is objectively true, but rather that our reality is created by us, in relation to our contextual and social understanding. The idea that humans acquire knowledge “partly through our bodily engagement” (Smith et al., 2009, p. 198), a notion coined ‘embodiment’ and developed by Merleau-Ponty (1962), is also central to IPA.

Lastly, it is worth noting that the principle of theoretical transferability underscores IPA’s aim of capturing the lived experience and understanding how individuals make sense of these experiences (Smith et al., 2009). This means that while studies using IPA focus on specific participants and contexts, the insights gained can be applied to those others with a sufficient degree of similarity, thus providing broader theoretical implications (Smith et al., 2009).

2.5.2 *Rationale for choosing IPA*

With its focus on understanding the lived experiences of individuals, IPA is well suited to a project centred on the exploration of mothers’ experience of caring for their daughter with AN. IPA seeks to examine individual experiences closely, and the meanings and significance that individuals place on them (Smith et al., 2009). Although it recognises that particular and subjective accounts can illuminate divergences as well as convergences across a specific phenomenon, it posits that “insight into the individual” may result in the achievement of “insight into the whole” (Caldwell, 2008, p21). The complexity of this research topic lies in how mothers’ meaning-making is shaped by, and reflective of, their own history. IPA will enable the exploration of these multi-layered narratives, helping to capture how their past experiences and individual context intersect with their caregiving journey, and uncover both the unique and shared elements of their experiences. The depth of exploration that IPA provides, will be essential for addressing the nuanced challenges these mothers face, and therefore help provide an initial insight into the kind of support these mothers might need. Other approaches were also considered, including discursive methodological approaches and Grounded Theory. Despite the latter being seemingly more focussed on social processes than the lived experience, it has been considered the first alternative to IPA (Smith et al., 2009), and with an exploratory and adaptable nature, could have offered valuable insights in the form of text analysis and theme identification. There was however too great an emphasis on theorising, which may have resulted in a loss of the vital depth and idiosyncrasies within each participant's account. IPA attends more closely to meaning making and interpreting (Cuthbertson et al., 2020).

Discursive approaches, including Foucauldian Discourse Analysis and Discursive Psychology, aim to understand how a phenomenon is made sense of and experienced by individuals through the use of discourse (Eatough & Smith, 2008). However, the emphasis placed on the linguistic construction of participants' experiences (itself a reflection of discursive approaches' strong commitment to a social constructionist epistemology), could have diverted attention away from the lived experiences and sense-making of the participants. IPA strives to interpret how sense is made of experiences (Reicher, 2000), and was deemed the research methodology most appropriate here.

2.6 Data Collection

2.6.1 *Sampling*

While there is no firm rule on sample size in a study using IPA, suggestions indicate that a homogenous sample size of six to eight is deemed appropriate for doctoral research (Smith & Osborn, 2008; Smith et al., 2009). This is to balance the need for deep exploration and analysis with that to identify thematic similarities and differences between participants' experiences. Here a small volunteer sample of 6 mothers was obtained.

2.6.2 *Inclusion and exclusion criteria*

To ensure the exploration of only one phenomenon, and the production of rich data and subsequent analysis, a homogenous sample is crucial (Smith & Osborn, 2008). To obtain this, participants needed to meet various criteria for inclusion in the study (See Table 1).

Table 1. Participant inclusion criteria

Inclusion criteria
(i) English speaking
(ii) Aged 31 and above
(iii) Have experience caring for a biological daughter with AN, who had received a formal diagnosis between the ages of 15-25, and has been in stable recovery for a minimum of 6 months and a maximum of six years
(iv) Be a recovered anorexic themselves (either having had a formal diagnosis or meeting the SCOFF questionnaire criteria during the pre-interview screening)
(v) Have entered recovery before their daughter's diagnosis

The requirement for participants to be 31 or older was to ensure they had been of legal age when they had their daughter, calculated in relation to the age criteria for the daughters' diagnosis. Allowing for potential teenage pregnancies meant risking additional emotional upset for the participants, and may have affected the homogeneity of the sample, something deemed essential in IPA. This criterion facilitated a level of consistency across participants, particularly in relation to the life stage at which they had their child and subsequently became their carer, enabling a more focussed exploration of this particular phenomenon.

Initially, both mother and daughter needed to have received a formal diagnosis of AN to ensure validity. During recruitment however, after speaking to several potential participants, it became apparent that many mothers had never received a formal diagnosis despite being severely unwell and experiencing symptoms all commonly associated with AN today. The recent historical shift towards a more positive perception of mental health has thankfully resulted in increased conversation, acceptance, diagnoses and treatments for illnesses such as AN (Currin et al., 2011). However, it leaves behind an under-diagnosed generation, the very generation I was trying to recruit. To ensure undiagnosed mothers would also be given voice, the relevant was changed so that potential participants would either hold a formal diagnosis or meet the necessary score on a screening tool for detection of EDs, known as the SCOFF questionnaire, a five question instrument developed by John F Morgan and colleagues (1999) often used prior to clinical assessment when an

ED is suspected (See Appendix 1). However, the SCOFF questionnaire is not retrospective; therefore, in the absence of a better alternative, the questions were adapted to read in the past tense. Participants' daughters had to have received a diagnosis between the ages of 15-25, as this is the age range that sees the highest number of diagnoses and the need for parental care (Haigh & Treasure, 2003; Zipfel, 2015). The study also required them to have been in stable recovery for a minimum of six months and a maximum of six years at the time of interview. A maximum of three years in recovery was initially chosen, but after recruitment proved difficult, a time period of six years was deemed to still be close enough to the event to ensure accurate recall. The participant was also required to be in full recovery, which in the context of this research, meant free of all active symptoms, with a healthy BMI, and no longer in ED focussed treatment. The need for participants to have entered recovery before their daughters' diagnosis was because the aim of the study was to explore their experience caring for their daughter having *previously* had anorexia.

A decision was made to only interview biological mothers to align with the majority of existing research, and to ensure homogeneity of experience.

Comorbidity within other forms of psychological illness is a remarkably common presentation in AN (AL-Asadi et al., 2015), meaning many suffers will experience one or more additional diagnoses in their lifetime, including other EDs. Consequently, participants were not excluded if this was part of their experience.

2.7 Recruitment

2.7.1 *Advertisement*

A recruitment flyer (see Appendix 2) was designed and used to advertise the research project. The flyer was shared via email with ED organisations that provided helplines for both sufferers and carers, and/or campaigned for better funding and knowledge for and around EDs. These included Anorexia and Bulimia Care, Beat[10], the National Centre for EDs, Seed, New Maudsley Carers – Kent, and online forums such as F.E.A.S.T and EDGI. The research was also conducive to snowball sampling, and anyone I contacted was therefore encouraged to disseminate the study information. To further aid recruitment and visibility of the study, the flyer was shared on the social platforms LinkedIn, Instagram, and Twitter. The study was advertised UK wide, and to facilitate participant

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[10] 'Beat': The UK's leading ED charity; 'New Maudsley Carers': UK based parent support group; 'EDGI': Organisation conducting a genetic research study of EDs.

accessibility, the options were offered to conduct the interview either in person at City, in the participants' home, or over video call on Zoom, depending on participant preference. It was hoped that developing a multifaceted recruitment strategy such as this, would aid in reaching a broad range of potential participants.

2.7.2 *Initial contact and screening call*

Once initial interest was communicated via the email address on the recruitment flyer, a screening call was arranged. Within the call, I gave the potential participants more information on the study, asked eight pre-interview questions (see Appendix 3), and administered the SCOFF questionnaire if necessary, to ensure they met the study's inclusion criteria. This call also provided an opportunity for them to ask any questions. Those that were not suitable for participation, either because they did not meet the criteria or were deemed at too high a risk of experiencing "adverse emotional reactions" (Draucker, 2009) were gently informed at the end of the call, or over email, after discussing this further and confirming with my supervisor. Those that met the research criteria were sent the participant information sheet (see Appendix 4) via email shortly after, and encouraged to ask any further questions before confirming their willingness to participate via email within a week. We then arranged a date and time for the interview, and I sent over the consent form (see Appendix 5), which I asked them to complete and return to me before the interview. All participants were given another opportunity to ask questions before the interview began.

Six participants were recruited and interviewed between November 2022 and July 2023.
All interviews were carried out over Zoom, which meant I was able to reach people in a wider geographical range across the UK than in-person interviews would have permitted (West Midlands, South East, North East). See Table 1 for further sample details.

Table 2: Participant demographics (pseudonyms used to ensure anonymity).

Name	**Age**	**Ethnicity**	**Employment status**	**Highest level of education**	**Relationship status**	**No. of children**	**Diagnosis or SCOFF**
Sally	54	White British	Employed FT	Undergraduate degree	Married	Two (18 & 16)	SCOFF
Beverley	51	White British	Self-employed	Undergraduate degree	Married	Two (20 & 15)	SCOFF
Janet	51	White British	Employed FT	Undergraduate degree	In a relationship	One (21)	Diagnosis
Jackie	59	White British	Employed FT	Undergraduate degree	Married	Two (29 & 27)	SCOFF
Anna	57	White British	Retired	Undergraduate degree	Married	Two (21 & 20)	Unsure – SCOFF*
Ruth	55	White British	Employed FT	Masters Degree	Divorced	Two (16 & 22)	Diagnosis

*Anna had no recollection of receiving a diagnosis, but when going through her old medical records in preparation for our interview, she noticed it said anorexia. The SCOFF questionnaire was completed as a precautionary measure, to ensure research criteria adherence.

2.8 Interview Process

2.8.1 *Interview schedule*

When using IPA, the most common and popular data collection tool is semi-structured, one-to-one interviews (Willig, 2013), as they help draw out thoughts, feelings, and stories in great detail from the participants (Reid et al., 2005). As the research aimed to explore previously anorexic mothers' experience of caring for their anorexic daughters, semi-structured interviews seemed a beneficial way to facilitate this, eliciting a deep richness of data, and providing the researcher with the flexibility needed to delve deeper into any important or interesting areas that might arise unexpectedly, resulting in the production of new ideas, learnings and concepts (Dearnley, 2005). However, this style of interviewing can demand a significant investment of labour and time from both the interviewer and interviewee, and may induce a reluctance to participate due to a nervousness around sharing stories of a sensitive and personal nature with a relative stranger. Furthermore, the semi-structured nature of the interviews means that depending on what and how much participants wish to share, interviews can venture down differing paths, with content also at risk of being impacted by the researcher/participant power imbalance, which may see some participants trying to be a ‘good’ participant, in addition to unintentional guiding of the interview direction by the researcher. With this in mind, an interview schedule was created (see Appendix 6), consisting of nine open ended questions, with additional prompts, that looked into areas of interest. The development of the schedule was influenced and inspired by previous research studies that explored the role of caregiver, in addition to my own considerations regarding the key areas I wanted to explore based on the research objectives. The initial draft was shared with my supervisor, to ensure the questions were well-suited to the research aims, were ethically sound, and were sufficiently open-ended allow for the generation of rich, qualitative data.

Interviews lasted between 60 – 90 minutes and were recorded using the Olympus DS-9000 Dictaphone. Before the interview, the purpose of the study was outlined once again, the interview format explained, and an opportunity was given to ask any remaining questions. Participants were then asked to verbally complete a demographic questionnaire (see Appendix 7), to help better contextualise the interview data and highlight any existing sample homogeneity and heterogeneity.

Post interview, I sent participants a debrief form (see Appendix 8), which included contact details for Beat, Mind, and Anorexia and Bulimia care, in case they had found any part of the interview distressing and felt they needed support. The form also encouraged them to contact me or my supervisor if they had any further questions.

2.9 Ethical considerations

The topic of this research required asking individuals to speak of, and share intimate details about, circumstances that existing research suggests could have caused considerable emotional distress. To ensure adherence to the ethical requirements and guidelines of the BPS (BPS Code of Ethics and Conduct, 2018; Code of Human Research Ethics, 2021), participant wellbeing therefore took precedence over all other ethical considerations, and I implemented the following measures.

Although the screening call was carried out to confirm that potential participants met the inclusion criteria, it was also an opportunity for me to gage the presence of emotional or physical vulnerability, particularly in relation to their own, or their daughter’s recovery. This was the case for one individual: after speaking to her, and discussing my impressions with my supervisor, both mother and daughter were deemed too vulnerable to take part, and I informed the mother that participation would not be possible at this time.

As stated above, all six eventual participants were given a full explanation of the purpose and nature of the study, and of what was expected of them, both verbally and in writing in the form of the participant information sheet. They were given several opportunities to ask questions, and informed consent to participate and allow recording was obtained prior to interview via the consent form. Participants were also made aware of their right to pause or withdraw from the interview at any moment, and to withdraw their data at any point in the three months following the interview. In each instance, I endeavoured to conduct the interview in a sensitive manner and ensured that participants were feeling a sense of emotional stability by the time the meeting concluded. I did this by checking with them how they were feeling, how they had found the interview, and providing space for them to share any further comments or feelings with me. Almost all participants became emotional at one point or another during the interview, with one pausing for a few minutes to collect her emotions. However none reported feeling distressed upon finishing – rather, all expressed their gratitude for me conducting my research in this area, and said they were pleased they had been able to help. The aforementioned debrief sheet was provided nonetheless to mitigate any distress that could have arisen later, and a further opportunity to ask any questions.

Confidentiality and its limitations were explained to participants prior to the interview, and they were reassured that all identifying information and personal details would be removed or changed to ensure complete anonymity and protection. They were informed that audio recordings and transcripts would be encrypted and securely stored, all data destroyed after the study's completion, and all other records kept for 10 years, as recommended by City, University of London. Participants were given the right to receive a copy of the published findings of the study if they so wished, as indicated by them on the Consent Form.

The interview was similar in format to therapeutic work, therefore it was important from an ethical standpoint that the purpose of the interview was made evident throughout - that it was not an offering of therapeutic support, but rather a gathering of data for a doctoral research project – not only for the participant, but also for myself. At the time of all interviews, I was working on placement in a private ED service. On one hand, this was a significant advantage as I was accustomed to, and comfortable with conversations surrounding AN and other EDs, and the profound emotional responses that they can elicit. However, it also meant an increased possibility of boundary blurring on my part. It was therefore important that I found a way to ensure that my roles as therapist and researcher were clearly distinguished and balanced. The fact that the interviews were conducted online from my home (via videoconference) - whereas my therapeutic work was mostly conducted from the placement offices – was a help. I also always ensured I took a moment before each interview to focus my mind on the goal in hand, the purpose of the interview, and the role I was about to adopt.

To ensure further safeguarding of myself, I carefully monitored the emotional impact of each interview, knowing that supervision and personal therapy were open to me if needed.

Ethical approval was granted by the City, University of London Psychology Research Ethics Committee – reference ETH2122-0365 (See Appendix 9)

2.10 Analytic strategy

An inductive form of analysis is used in IPA, that acknowledges the researchers' immersed, introspective, and interpretative involvement in the process of analysis and knowledge formation (Reid, 2005). This aligns with the hermeneutic roots of IPA (Pietkiewicz & Smith, 2014), as it is those interpretations that facilitate the generation of new findings, providing greater insight into the phenomenon being explored.

I attempted to approach the data with two different objectives. The first was to make sense of and describe the participant's reality by honing in on their idiosyncratic experiences. At this stage, the primary goal was to provide an intelligible, third-person description, whilst remaining close to the viewpoint of the participant (Smith et al., 2009). The second objective was to carry out an interpretative analysis, by placing the first description in the context of a larger cultural, social and theoretical picture, whilst inquiring into the meaning of an experience for a participant (Larkin et al., 2006). The inductive and iterative characteristics of the flexible IPA process, mean the researcher is able to move from experiences that are particular to experiences that are shared, and therefore from description to interpretation (Smith et al., 2009). The concluding stage is a written narrative report of the research, in which participant accounts will explain and illustrate the Group Experiential Themes, resulting in the ability to detail and link identified themes to available literature (Pietkiewicz & Smith, 2014)

Prior to analysis I transcribed all interviews verbatim, changing the margins to create space on both sides of the transcript for handwritten commentary and notes. Due to the idiographic nature of IPA, I analysed the interviews one at a time, each time following the seven steps outlined below. Analysis of the data was guided by the updated terminology outlined by Smith, Flowers and Larkin (2022).

Step 1 – Reading and re-reading

This first step involved reading and re-reading the transcript, line by line, multiple times whilst listening to the audio to ensure accurate transcription, resulting in full immersion into the original data. I found this truly helped me to re-familiarise myself and connect with each individual participant and their experiences.

Step 2 – Exploratory noting

Here I aimed to note down any and all reflections or reactions I had by hand, on the right-hand side of the transcript (see Appendix 10a). I underlined anything that struck me, writing why it felt important, with a particular focus on what that suggested about the world of the participant when possible. Exploratory notes tend to examine data semantics and language, whilst staying close to participants' individual accounts, and therefore my notes were mostly descriptive, linguistic, and conceptual, but also commented on elements such as pauses, laughter and repetition.

Step 3 – Experiential statements

This step saw the construction of experiential statements (ES), which helped to consolidate the large volume of notes that had been generated in the previous step. It required an analytical shift, where I attempted to produce succinct summaries of the features and information I found significant whilst aiming to reflect my understanding of the participant's experience whenever possible. Whilst the result of my interpretative work, it was important that these summaries remain a reflection of the original thoughts and words of the participant (Smith et al., 2022), and also that they be anchored in, and supported by the data, honouring the hermeneutic circle[11]. Statements were written down the left-hand side of the transcript text (see Appendix 10b).

Step 4 – The search for connections across Experiential Statements

This was an opportunity to identify patterns, similarities, and connections across ES, and to start mapping them out to see how the statements fit together. A copy of the annotated transcript was made, and then ES were cut out on their own individual pieces of paper. Page numbers were noted on each so that their location in the transcript was easily identifiable. ES were randomly placed on the floor to remove ordering, in search for more conceptual groupings (see Appendix 11a). Statements were moved around, in an attempt to group similar statements together to best show their interconnections, and I continued this process until I had thematically titled each cluster of ES. This grouping process can be seen in action in Appendix 11b.

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[4] A process iterative in nature, involving the movement between the whole and its parts, with each informing the interpretation of the other (Smith et al., 2009).

Step 5 – Naming Personal Experiential Themes (PETS)

The titles given to the clusters of ES to describe their characteristics, developed in Step 4, became each participants *Personal* Experiential Themes, and, as advised by Smith et al (2022), were organised and consolidated into a table, alongside the ES's and direct quotes from which they initially emerged (see Appendix 12 for table example). A few experiential statements were discarded in this process if not relevant to the question, or were combined with another possessing the same meaning.

Step 6 – Repeating steps 1 – 5

This step refers to the repetition of steps 1-5 on the remaining transcripts.

Step 7 – Group Experiential Themes

Step 7 required the identification of similarities and differences within the PETs generated for each participant, in order to create a set of Group Experiential Themes (GETs) (see Appendix 13). GETs serve to display the unique and shared features of participants' experiences, whilst reflecting the experience of the group as a whole.

2.11 Quality and Validity

There are multiple perspectives on how to evaluate quality and validity in qualitative research (Finlay, 2006), and therefore, a number of different guidelines (e.g Finlay & Evans, 2009; Elliot et al., 1999; Yardley, 2000). As recommended by Smith et al., (2022), and therefore consistent with IPA, this study follows Yardley's (2000) guidelines, which centre on the following four criteria:

2.11.1 *Sensitivity to context*

Sensitivity to context requires an awareness of how the research process may be impacted by existing external factors and should be exhibited throughout by the researcher (Smith et al., 2009). This can be achieved by conducting a thorough assessment of the existing empirical data and literature, and ensuring a sensitivity to sociocultural context (Yardley, 2000). My choice of analysis – IPA, which aligns with my epistemological position, and my commitment to answering the research question in accordance with its focus on the lived experience and idiography, addressed this. Furthermore, as contextual sensitivity plays an important role within IPA (Smith, 2003), participants' ethnic and sociocultural backgrounds were held in awareness throughout the research process, from the construction of the interview schedule to the write-up of the project itself. This was of particular importance within this study, as these differences can have a direct impact on the type of support accessible to carers. Furthermore, the holding of an awareness surrounding the impact that ED care can have on societies, economies, healthcare systems, social perceptions and caregiver wellbeing, was maintained. The inclusion of a demographic questionnaire also enabled me to form a better understanding of my participants' background, and therefore any subsequent variations in perspectives and experience.

2.11.2 Commitment and rigour

When designing and carrying out the research, commitment and rigour were attained via a deep engagement with the topic; immersion in the data; and a rigorous effort to prioritise transparency and attention to detail (Smith et al., 2000; Yardley, 2000). Furthermore, to develop a strong foundation upon which to construct the research, supervision was utilised regularly in the early stages. Yardley (2000) also stated that "commitment and rigour might be demonstrated by the effective use of prolonged contemplative and empathic exploration of the topic. Throughout the three and a half years of this project I worked to develop my expertise and skills in the chosen research method. I further used supervision and my reflexive journal to reflect on the research process at every stage.

2.11.3 Transparency and coherence

This criterion is essential to ensure the reader has clear understanding of the research process, what has been done by the researcher, how, and why (Yardley, 2008). To adhere to this, clear descriptions have been offered for each step and decision made throughout, in addition to staying as close to participants' lived experiences as possible by using their own words during the analysis. A good fit between the method of investigation, epistemological position, research question and analysis was also ensured and has been outlined, to address coherence (Yardley, 2000).

2.11.4 Impact and importance

Impact and importance relate to how the research contributes to the field socio-culturally, theoretically, or practically (Yardley, 2000). This research aimed to shed a new and meaningful light on an overlooked phenomenon, by improving understanding of the experience itself and highlighting any impact it may have on the care given and on the carer themselves, thus leading to improvements in the support offered to recovered parents caring for a child with AN. It is hoped that it has also provided some reassurance to those that participated, that their experience is being recognised, considered and taken seriously. Impact and importance will be discussed further in the discussion section.

2.12 Reflexivity

A qualitative methodology was a natural fit for me, as it aligns with both my personal and professional values as a CP trainee. The richness of the human experience is welcomed within the qualitative approach, as it is within CP. When embarking on this research, I wanted to give a voice to these mothers, to hear their stories, experiences and perspectives, and, through the nuanced lens that qualitative methodology offers, I feel I have been able to achieve this. I was however aware through existing research that the research and analysis could be subject to my own personal biases, due to my own 'lifeworld' influencing the process of interpretation (Smith et al., 2009). I found an example of this to be true in the early stages of my interview schedule construction. Perhaps my interest and extensive exploration in the area had unknowingly pre-informed some expectations, because I noticed some questions read a little leading, possibly suggesting that caring for a daughter with AN when you too had experienced the illness was more difficult than if you had not. Upon recognition of this, I amended the wording to ensure a more neutral stance, to avoid participants feelings compelled to answer in line within a certain frame. Going forward, I endeavoured to 'bracket' any further biases, existing knowledge and preconceptions to extent that I could, to allow the unique and rich experiences of the participants to emerge.

The recruitment process proved more difficult than expected, taking five months and four ethical amendments from the date of ethical approval for my first interview to take place. Despite being contacted by seven people during those months, none met the full criteria. However two almost did. One had not received a formal diagnosis, and the other's daughter, although she had been in recovery for 8 months, was still receiving support and not free of all symptoms. I found myself feeling restricted by my criteria, worrying I was going to lose out on participants that would be invaluable to the study. I shared this with my supervisor, explaining – as stated previously – the generational differences regarding conversations and opinions about MH and the subsequent impact on diagnoses, and that defining recovery as being 'free of all active symptoms, a healthy weight, and no longer receiving any kind of support' particularly for the daughter, could mean I would never be able to recruit enough participants. AN recovery is complex, with some research suggesting that for many, it never truly leaves you (Gaudiani et al., 2002). In agreement with my supervisor, I decided that daughters would need to have had a stable and healthy weight or Body

Mass Index (BMI) for a minimum of six months, but could still be in therapy and engaging in some behaviours. This was to be established during screening calls, assessing eligibility case by case using my clinical judgement, with the risk and well-being of the mother/participant held at the centre of the final decision at all times. The second potential participant ultimately stopped responding, but because of these changes, the mother without a formal diagnosis was my first interviewee. I was also able to conduct a further three interviews, with women who would not have qualified under the initial criteria. Recruitment was then further boosted by the circulation of my flyer to the New Maudsley Carers community.

I found the interviews themselves to be powerfully enriching experiences that will stay with me for a long time. I felt immense empathy for all that the participants had been through, and gratitude for their willingness to share their experience so openly and express such vulnerability. This however made it even more important that I established my role of researcher early on, as I discovered in the first interview how easy it would be to slip into the CP role. Fortunately, I feel by the end of that first interview I had found the right balance between researcher and CP – able to cover all questions and explore all areas I was aiming to, whilst maintaining a curious stance, and retaining a flexibility that allowed the participant to lead and share organically.

Although a lengthy process, I enjoyed the transcription stage, as it provided an opportunity to reconnect with each participant, and with their personal story. I felt exploratory noting and creating ESs connected me even further to the meaning of the data. However initially I was unsure how much, or little, to comment on, and not wanting to miss anything meant I was left with a large number of ESs, and therefore had far too many PETs - I was able to reduce these by combining themes. At first I also struggled to maintain a phenomenological angle, meaning at times my notes were overly descriptive and analytical, and some of my PETs corresponded too closely with interview questions. After a conversation with my supervisor, I was able to recognise these patterns and rectify them, choosing to use participant language wherever possible to ensure the protection of their authentic experiences and storytelling. When repeating the process, I was aware that being “influenced by what you have already found” (Smith et al., 2009) was likely. So, to avoid looking for themes discovered in previous transcripts, I committed to remaining aware of any existing understanding or assumptions, and I approached each transcription openly and with a curious stance. Despite these challenges, and my continued apprehension throughout the whole analytic process that I was not doing my participants justice by giving a sufficient voice to their experiences, I loved delving into the data and co-constructing meaning, particularly during Step 4 when I was physically mapping out possible themes.

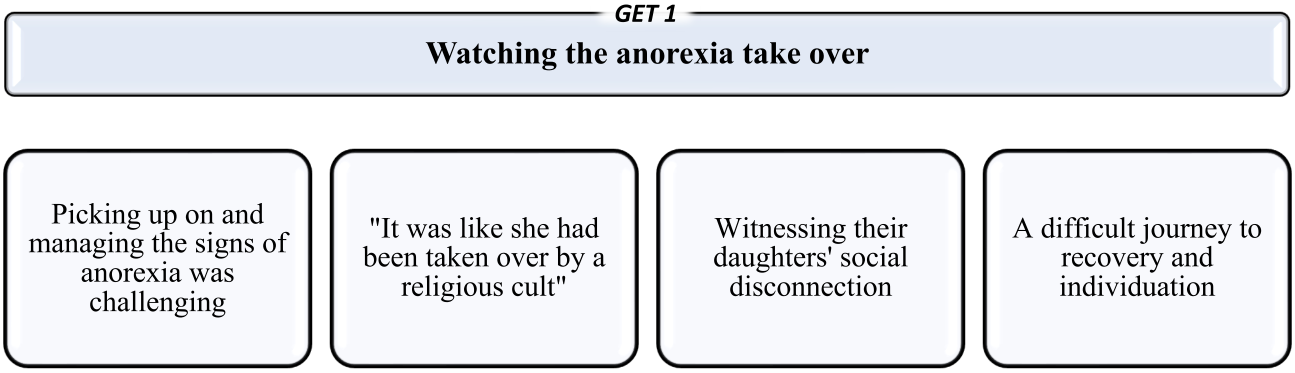
3 ANALYSIS

The following chapter presents a comprehensive narrative account of the analysis of six interviews conducted to explore the lived experience of participants, in relation to the research question; “What is the lived experience of recovered anorexic mothers, caring for their anorexic daughters?”. To ‘give voice’ to participants, and to ensure transparency (Larkin et al., 2006), direct quotes have been taken from the transcripts, and a tentative, interpretative stance has been adopted at all times, something deemed essential given results are considered a “co-construction between participant and analyst” (Osborn & Smith, 1998). To stay as close as possible to the participants’ lived experiences, no reference will be made to existing literature or psychological theory, as recommended by Smith and colleagues (2009).

Not all data could be used for analysis given the large quantity collected. Therefore, the quotes selected are those considered to provide the clearest depiction of the themes generated. This process involved paying careful attention to ensuring that each participant’s voice is represented, that experiences are reflected in their entirety where possible, and that meaning and context have not been altered. Furthermore, as the transcription was verbatim, speech idiosyncrasies, pauses and grammatical errors have not been removed or corrected. Pauses are demonstrated by three dots … , emphasis will be underlined, and any data not deemed directly pertinent, and therefore removed, is noted with three bracketed dots […].

From the analysis, six Group Experiential Themes (GETs), and 28 subthemes emerged. See Figure 1. below.

Figure 1. Group Experiential Themes and Sub-Themes



GET 2

Healthcare - A broken system

- Both mother and daughter were unable to get the support they needed
- A reductionist, one size fits all approach
- Not ill enough
- "There is not a lot of help out there, and you have got to find the resources yourself"
- A poor standard of care - "It is just not good enough"
- It was not all negative

GET 3

A heavy emotional, cognitive and physical toll

- Mother's physical and mental health suffered
- Fearing for daughter's life
- The burden of self-blame
- A heavy sense of responsibility
- It is all consuming
- The anorexia controlled the mother too

GET 4

A strained home and family life

- A family life in lockdown
- A complicated, challenging, and abnormal mother/daughter relationship - "It was like parenting a toddler."
- Witnessing the negative impact on husbands and siblings
- Seeing the deterioration of the father/daughter relationship
- Husbands lack of understanding and engagement tested marriages

GET 5

Mother's own AN experience - A double edged sword

- Mother's own experience was helpful
- With a greater understanding, came fear, collusion and false hope
- Own anorexia was triggered, and came "creeping back in"
- Recovered parents enter the carer role, with their own AN following closely behind - "I don't think it ever goes away"

GET 6

Caring for a daughter with AN - Surviving the role

- The vital role of work and friends
- Speaking to other carers was a "lifeline"
- Alternative methods to keep you afloat
- Learning, reading, and researching

3.1 Group Experiential Theme 1: Watching the anorexia take over

This first theme explores the mothers’ experience of witnessing first-hand the illness consume their daughter. Participants shared at length the experience of noticing the initial signs of anorexia, and the pain of seeing how their daughter changed because of the illness, not only in their behaviour and personality, but also in other areas of their lives. The majority of participants also noted that getting their daughter back to health was, and is, not a straightforward process.

3.1.1 Picking up on, and managing the signs of anorexia was challenging

All participants made reference to behaviours their daughters adopted during their illness, or ways their appearance or personality changed. Four elaborated further on how this was to experience, with Helen describing the moment she and her husband realised something was wrong:

> *"We noticed that Maddie sort of, put her napkin over her mouth and then went to the bin, and Mike, my husband said, 'Maddie, what, what did you just do? What just happened?' And um, she burst into floods of tears and, and she said, oh I don't know, I'm really struggling eating, and you know, kind of so, there was obviously lots going on by that stage, lots of restriction." (Helen, p.6)*

Helen’s description demonstrates how confronting it can be to first see the reality of an ED, and her somewhat fractured narrative may indicate how challenging, recounting the details of a moment tied to such emotional distress is. Mike’s struggle to speak, and double questioning, particularly “what just happened?” suggests confusion and disbelief at what they had witnessed, something then mirrored by Maddie not understanding what was happening either. This captures an emotional, shocking moment for the family, with Helen’s final comment implying that despite this being the first they had seen of the AN, it had already got its claws in and progressed, seemingly confirming this shortly after:

> *"Six weeks in, I remember we, sat with her and we said Maddie you know, you're really, we're really worried about you, you are really underweight, and you know, getting worse and worse, we just, we've got to do something about it, because there's only, you're only going one way at the moment, and that is into hospital because we can't, this is, it's just not, it's not right, it's not healthy." (Helen, p. 8)*

Maddie was now visibly unwell, causing her parents distress. The notion that the AN was only gaining momentum and strength is conveyed, leaving Helen perhaps feeling increasingly powerless. The desire to "do something" could therefore be seen as an attempt to gain this back, attempting to put the brakes on enough to avoid hospital. I wonder whether the reality of hospital scared her. "It's just not, it's not right" captures a possible struggle coming to terms with the illness, and a mix of frustration, worry, and desire for Maddie to be well. I felt a sense of desperation as Helen spoke, that I imagine they were feeling by the time they "sat with her", something seemingly akin to an intervention. Helen later shared that this made her daughter "furious with us, she was like how dare you" (p. 8), due to "complete denial" (p. 8).

An increase in anger and frustration was also reported by Claire:

> *"Um, the change in aggression, the, you know, the effing, effing, effing, and hitting is hard." (Claire, p. 17)*

A description of verbal and physical abuse is given, with the repetition of 'effing' emphasising the idea that this was not a one-time occurrence, but an ongoing challenge for Claire, and as understood from the word "change", not a trait of her daughter's she was accustomed to dealing with. This type of behaviour was strongly echoed by Sarah:

> *"She would, in her worst moments, have these absolutely horrendous, um, meltdowns, frenzies. When she would wreck her room, she would threaten to kill herself, she would want to end her life. Um, and I, I would sometimes meet that with my own anger, um, until I learned to be calm about it." (Sarah, p. 17)*

I was struck by Sarah's descriptions here: "Meltdowns, frenzies, wreck her room" all provide a real insight into what it was like to experience being around Sarah's daughter when she was at her worst. The quote captures a sense of chaos, with emotional outbursts and loss of behavioural control on both sides.

Participants also reported becoming aware of secretive behaviour too, most notably exercise. An example of this is described by Claire:

> *"She did sit ups all night, she ran down, we're on a farm, and she'd put a heavy coat on, wellies, and run down the plough field doing star jumps and she'd come back and say 'I only went to the hedge' and I thought I've stood upstairs on the bathroom windowsill, watching you and that's what you've done. Um, so yeah, it was very hard." (Claire, p. 5)*

We see here how Lilly would lie to Claire, but also how Claire had begun to watch Lilly, perhaps to monitor her changing behaviour. I got the sense that Claire knew what she would see when she watched through that window. Perhaps that had become a difficult normality that Claire felt powerless to stop, illuminating the complex relational and emotional dynamic. Helen experienced something similar:

> *"We literally had to you know, take her running shoes away […] then she started swimming […] it was mad, mental, she'd do 200 lengths, and I was just like, she said 'Julie said I could swim' (her therapist). […] Julie said she could swim 20 lengths." (Helen, p. 16).*

Here Helen expressed her own experience of managing the secretive behaviour that comes with the AN, but hinting that whatever you do, the AN will find a way, suggesting a never ending battle.

A poignant change most noted, was their daughter's changing appearance. Throughout the interviews I heard "She was like a stick" (Claire, p. 6), "She was skin and bone" (Helen, p. 10), "She was looking quite ill, like she was very, very pale" (Janet, p. 5), but the following comment from Sally describes another side to this visible change:

> *"She's starting a little bit to wear clothes that aren't so baggy, because she just wore really baggy clothes. She wouldn't wash, um she didn't brush her hair, um she wore dirty clothes. It's all on the outside looks absolutely awful, but it's all part of the illness, and I understand." (Sally, p. 8)*

This additional information about the physical decline feels significant. AN is not just weight loss, Sally had to watch her daughter stop taking care of herself, becoming a shell of who she once was. Nevertheless, Sally was able to find a place of understanding, and a reluctant acceptance perhaps, about what she was seeing, but her tone change and reduced pace of speech indicated a great sadness when thinking back to this time.

3.1.2 “It was like she had been taken over by a religious cult.”

Most mothers relayed the feeling that they had lost their daughter to the force that is anorexia, with Helen telling me:

> *"We picked up on it quite early, but it was like an intercity route. I just could not stop it. It was, just absolutely got her, it got into her head." (Helen, p. 7)*

The early detection of the AN seemed to make little difference, it was charging ahead. *“Intercity route”* suggests an unrelenting, pervasive force, that was difficult to help Maddie divert from. Both quotes present the idea that it consumed Maddie, getting “into her head”, taking away from who Maddie once was, resulting in a sense of loss for Helen. A feeling of powerlessness is also expressed. Helen further commented:

> *“When she was in the depths of it, it was like, she'd been taken over by a religious cult. We just could not get hold of her. We could not. It was like, it wasn't Maddie. It was, um I think because of that, she did feel really distant.” (Helen, p. 18)*

Janet described a similar feeling:

> *"The eating disorder was in control. The eating disorder was in control all the time. That was her friend, no one else was her friend, she only listened to the eating disorder.” (Janet, p. 9)*

Both Helen and Janet convey that their daughters grew distant, that they could no longer get through or close to them. They were stuck on the outside, powerless. “It wasn’t Maddie”, communicates the idea that Maddie was almost possessed. I was further struck by Helen using the term “religious cult”. Cult-like ideologies are known to be extreme, involving high levels of control, with members possessing obsessive, rigid beliefs, and a desire to conform and follow. This mirrors their experiences, seeing their daughters in a cult of their own, in which AN was the leader, and Maddie and Hannah were members.

Janet's repetition of control, and addition of "all the time" emphases the unwavering nature of AN and the impact this had on them, with Sally also describing this, including where she saw that control taking her daughter:

> *"I kept saying to her, you know you're struggling. We need to go to the doctor.. 'no I'm fine, no I'm fine', and I work in mental health [...] I'd know all about poor people in hospital being fed through tubes, in their nose, and I was thinking, I don't want that for my daughter. I just, I just could see where it was going if we didn't stop it, and I couldn't see it, that she was going to be able to stop it herself. I really couldn't." (Sally, p. 5)*

This suggests that Sally could see how deeply entrenched the illness was, and that she knew there was no way for Hannah to find her way back without help, as emphasised by the repetition of "I couldn't see it.". Sally having insight into what being an inpatient is like seemed to help her find the strength to challenge Hannah, in a bid to avoid, and ultimately protect Hannah from that fate.

Claire sadly saw that become a reality:

> *"It made me think because I had gone through it, got better, I would be able to help her, we'd manage, we'd get through it easily, and we, it didn't help, whether it made things worse, I'm not sure, but it certainly didn't. She was, she got as bad as she possibly could have done *laughs*." (Claire, p. 10)*

Despite like Sally, trying to help her daughter avoid the worst, and feeling optimistic that they would succeed, the insidious power behind Lilly's AN won, and she "got as bad as she possibly could have done.". Claire then laughed, which given the context may seem strange, however I found it to be indicative of pain. Perhaps a way of coping with the depth of emotion that accompanied that time in their life, or a form of emotional dissociation to manage distress. Alternatively, this may capture disbelief, that despite their efforts, Lilly reached the point of severity that she did. Claire was not the only participant to laugh after sharing something painful.

3.1.3 Witnessing their daughters' social disconnection

Participants not only watched the anorexia take away from who their daughters used to be, but how it stole from their wider lives too. Sally refers to Daisy's lack of close relationships:

> *"Her brother has gone off to university now, he's two years older than her. They've never been particularly close, because she's not really close to anybody to be honest." (Sally, p. 11)*

As Sally shared this, it felt like I witnessed a moment of realisation for Sally, that this lack of closeness was not specific to Daisy and her brother, but in fact a reflection of Daisy's social life and relationships more generally. At the time of interview, Daisy had been weight restored for approximately one year, revealing how long other areas of life can take to return to normal. The reduced pace of speech, and sombre tone seemed to reflect a sadness in Sally.

Claire built on this:

> *"What was very difficult is, she cut herself off from all her friends, you know, so by the, she didn't want her friends around. Her 18th was hard, no her, school prom was hard. She'd lost a lot of weight, you know, and friends came nicely to be with her to go with her. But of course, they're all the thing about the dress, and then she didn't want photographs taken, but then she did want photographs. She was nervous of her friends coming over." (Claire, p. 13)*

This reflects the challenge of witnessing Lilly's inner conflict: wanting to participate in typical milestones but finding it difficult to do so, particularly after withdrawing socially. Claire misremembering the event could suggest that the last few years have been so distressing that it becomes blurry. Stating that her friends "came nicely", perhaps implies that Claire would have understood if they did not make that effort by that point, conveying a sense of gratitude, possibly as it facilitated a moment of normality. Claire also saw her daughter's romantic relationship break down:

> *"She withdrew from her boyfriend and that relationship has finished. Now he says it wasn't to do with the anorexia, but he was getting scared and he was ringing me and I say, you know, it's not you, she closes herself off. Ring Beat, he was very good, he tried to cope, but then he ended the relationship. Not saying it was because he couldn't cope, but you do wonder, do you know what I mean?". (Claire, p. 8)*

This shows how Lilly withdrawing affected those close to her, and how even her boyfriend looked to Claire for help. I notice that Claire advised him to ring a helpline, perhaps she did not feel she had the capacity to support him too? Furthermore, Claire's final sentence is a little convoluted, but revealed the sense that she did in fact think it was likely that he could not cope, and was perhaps looking to me for my opinion, or confirmation of that.

Ruth too observed her daughter's social isolation:

> *"Her friends were rubbish, they just stopped including her and it was obviously, you know, six months gone, life had moved on, and there was not a space really when she came back to school. And she struggled friendship wise for the whole of this year. Um, and in the end, she just kind of gave up on them because they, they'd arrange things and not invite her." (Ruth, p. 7)*

Holly had a sense of belonging before she got unwell, and Ruth watched AN take this from her. "Rubbish" implies that Ruth felt Holly deserved better. Friendships at school were not the only thing affected: both Sally and Claire shared the impact their daughter's illness had on their academic experience:

> *"September was a new change, she's eating with a small group of other packed lunch people. Whereas before, she sat in a classroom with a staff member there, and she used to take a friend with her." (Sally, p. 2)*

> *"We put things in place and she was coping you know, she didn't go to uni. She didn't feel as though she could cope with that." (Claire, p. 22)*

These quotes demonstrate the influence of AN on the school experience, and the possibility of further education. Both highlight that Sally and Claire had "put things in place", to help ensure their daughters safety and health. Both might suggest a difficulty in seeing how normal experiences were changed or taken away from them, something they will never get back.

3.1.4 A difficult journey to recovery and individuation

This final sub-theme was alluded to by all participants, whether about their own recovery or their daughters. Interviews revealed how difficult it is to escape the illness once it has taken over, highlighting the ongoing need for care due to the complexity of recovery, and the absence of a straightforward or linear route. Recovery can therefore be long and arduous, as experienced by Sally:

> *"You eat every day, and you can't avoid food *laugh*. So it's really, hard, obviously it's hard for her, and I do, see it's hard, she's terrified around food, you know, I think it's just, every day, it's just frightening for her to eat, and that's no different to 18 months ago, maybe it's slightly less frightening because she does eat more, but it's still frightening. The fear is still there." (Sally, p. 15)*

Sally reveals how stagnant the recovery process can become, particularly once reaching weight stability. The initial exclamation, perhaps underscores Sally's disbelief and frustration when trying to comprehend Daisy's struggle to engage with something deemed a fundamental part of life - her laughter further emphasising this. I noticed that after expressing it was "hard" for her, Sally quickly acknowledged her daughters' difficulties too, perhaps wanting to ensure a sense of awareness and empathy was conveyed to me, to demonstrate she possessed sufficient understanding as a caregiver. This captures the challenging dynamic of experiencing and managing your own emotions within the context of being a carer, which involves being mindful of, and prioritising your daughters' difficulties at all times.

Claire builds on Sally's experience:

> *"Now Lilly seems to be independent, she'll go off and do something. Then the next day she says, have I done the right thing? So although she appears very self-sufficient and independent, she's always looking for reassurance." (Claire, p. 18)*

This further illustrates the nuanced nature of AN recovery. Claire seems to believe her daughter to be 'recovered', and independent, yet Lilly's occasional reassurance-seeking highlights lingering insecurities, pointing to the ongoing, complexities of recovery, and the continued need for Claire as an active carer. Claire added:

> *"So she now, she seems much better, and a few months ago, she said to me, oh Mum, I can now think, my brain is now, I've got room to think about normal things.[...] And now she's done this all herself, so hopefully, you know, you're always going to have times probably*

> *when it comes back. But you know, that she had to remember all those strategies for dealing with it" (Claire, p. 8).*

This could signify a feeling within Claire that there might be a need for her care indefinitely, but expresses hope that Lilly will be able to manage any resurgences on her own, so she can continue to relinquish her carer responsibilities.

Ruth revealed that *how* her daughter eats will be an ongoing part of the recovery experience:

> *"I had to relearn how to eat normally, and I can see that in my daughter, she is putting on weight, but she doesn't eat normally. I mean, I'm pleased, I'm willing, you know, if she eats anything, that's, that's a bonus. But she's like me is going to have to relearn how to eat normally." (Ruth, p. 2)*

Ruth illustrates that the carer role is not as straight forward as helping her daughter to eat sufficient amounts again; it also entails addressing the *way* she eats it. Sally goes into more detail about a similar experience:

> *"She eats painfully slowly, she picks food apart, and examines it, and um, she has to normally read a magazine or have something on the iPad to distract herself while she eats." (Sally, p. 14)*

Both describe the abnormal way their daughters now eat, despite their recovery stability. Ruth likens Holly's behaviour to her own experience, suggesting a depth of understanding regarding what Holly is yet to face, that others might not have, eliciting the idea of a shared journey. Additionally, Sally describes what this eating may look like, evidencing a slow and meticulous approach. The word "painfully" and how Sally described this behaviour, suggested a sense of frustration at the slow progress, making me consider the possibility that Sally had begun to experience compassion fatigue. Ruth felt something similar:

> *"So, you know, I'm very much, a, you know, if you say you're going to do something you do it. Um, so it left me with a lot of frustration around, um being, taking one step forward, one step back, one step forward, one step back." (Ruth, p. 25).*

The lack of consistent progression appeared to leave Ruth feeling frustrated, wishing Holly would stay true to her word. I would imagine this back and forth was emotionally taxing for Ruth.

3.2 Group Experiential Theme 2: Healthcare – A broken system

This theme presents participants' experiences of healthcare - what support was available for their daughters and their opinion on it. Sadly, all participants shared their overwhelming disappointment. Comments included criticism of the accessibility and quality of support, including an apparent one size fits all approach, and treatment not being provided early enough into their daughter's illness. A few positive experiences were noted however, which will also be shared in the sub-themes below.

3.2.1 Both mother and daughter were unable to get the support they needed

Four participants described various difficulties when it came to getting professional help for their daughter. Janet shared her disappointment in the NHS:

> *"So we're not sure why she's bingeing, we don't know whether it's the recovery from the anorexia, but she's still going through that hunger stage. [...] We just cannot get the help on the NHS, at all. They've, they've been appalling. So we're just trying to get private health again. But we're really struggling to find someone." (Janet, p. 8)*

Janet's daughter was experiencing binging behaviour, which Janet seems to believe could be influenced by her recovery, and the extreme hunger that follows. Her confusion surrounding the cause is apparent, but while she sought professional help, she was unable to get this. The use of "appalling", suggests a moral outrage and deep level of disapproval. Janet felt she had no choice but to approach the private sector 'again', only to be met with same difficulty. She later learned that she was not the only carer to experience this:

> *"The NHS has let, let down eating disorders to be honest. And when I speak to other carers, a lot of them have had to go private, because they can't get the help." (Janet, p. 22)*

Stating that the NHS has "let down eating disorders" is damning. It communicates that Janet believes an entire group of people in the UK receive insufficient or inadequate care, which they likely had to fight for. The experiences of others further corroborate this, suggesting this is not an isolated experience:

> *"I think they, I think they might have offered us some CBT, but we were put on a waiting list and kind of, I needed something quicker than they could provide." (Helen, p. 28)*

Helen could not get what she needed, and was not willing to wait, suggesting that time was of the essence when it came to treatment. Despite the waiting list, Helen's comment suggests that she did not feel help was guaranteed at the end of the wait. The use of "us" perhaps conveys how involved Helen felt with her daughter's care from the outset, again linking to the idea of a shared experience.

Claire expressed similar frustrations:

> *"I mean, I nearly lost it when the local doctors wouldn't help, and didn't seem to know anything, weren't prepared to know anything. So the feeling that you're bashing your head against a brick wall." (Claire, p. 22)*

Claire reveals her frustration from not being able to get help, instead being met with reluctance, and what appears to be incompetency. Nearly losing it also implies that due to health professionals' lack of responsiveness, she was close to losing control of her own behaviour or emotions.

Significant frustration was also expressed in reference to turning 18 when you are in CAMHS care, as heard from Sally:

> *"And we're on a race against time, 'cause she's 16, and 17 in January and once you're 18, CAMHS will dump her. So we, I feel like, you know, we've gotta try, and get her as solid as possible before she's discharged, because I think once she's discharged, and she's 18, *sigh*. You know, you get very little leverage at that stage*" *(Sally, p. 8)*

Although care was being provided, Sally is displaying a sense of urgency and panic, as once her daughter turns 18, CAMHS care will no longer be available and new care post discharge may not be offered (something later supported by Janet's reflection: "*I think once you get to 18, that help is appalling"*. Sally sighed heavily when sharing this with me, perhaps capturing the heavy emotional weight accompanying this uncertainty. Sally later made reference to countries that provide better care:

> *"Only yesterday I was reading about, uh, what would you call it, approach in Sweden called, maybe called Mando, I don't know if you've heard of it?...They kind of take people*

> *through, and it last five years! *laugh* Five years! What does that say? Not chucking you out when you're 18" (Sally, p. 24)*

Sally is expressing clear disbelief at the difference in care offered in Sweden, with her laugh more akin to a disapproving scoff towards UK care. Something poignant from both quotes is the language used: *"CAMHS will dump her*", and *"not chucking you out".* This evoked the feeling that individuals are discarded like rubbish, suggesting Sally expects the upcoming discharge process to be somewhat of an abrupt abandonment, lacking in empathy, leaving Sally with no professional support.

It was not just help for Daisy that Sally could not get:

> *"The things that don't help, are not having the support is really hard, ok I take medication, but I need therapy, but I can't get it." (Sally, p. 21)*

Sally feels she needs support for herself, but cannot get this either, leaving her more vulnerable to emotional distress. This suggests a problem that perhaps spans wider than EDs alone.

3.2.2 A reductionist, one size fits all approach

Five participants described treatment to be standardised in nature, with no tailoring or adaptation made to fit the individual needs of their daughters, thus increasing the risk of ineffective treatment, and subsequently the distress levels of the mothers involved. Sally shared her experience of this:

> *"I looked at where her weight trajectory had been as a young, little child and she'd been on the 75th percentile. But CAMHS work off the 50th. I mean, that's like saying every child should wear size three shoes! I mean, it's nonsense, sorry, I'm just trying to, I have a particularly.." (Sally, p. 7)*

Sarah's disbelief is palpable. She seems unable to comprehend what she considers to be a nonsensical, generalised approach to her daughter's recovery. Sarah's pitch escalated as she recounted this, becoming increasingly animated, then stopped herself and apologised. This perhaps reveals how close to boiling point Sarah was when this occurred, and how raw this experience remains. It seemed that Sarah struggled to find her words afterwards, suggesting she needed a moment to regulate her emotions. She later reflected further on this:

> *"I think, they're going on their own time scales, and that has nothing to do with our timescale…..It's one size fits all" (Sally, p. 24)*

Again, sharing the belief that health professionals did not take anything about Daisy specifically, into consideration. This was a common theme:

> *"All the way along, it's felt like, this is the model we use, you have to fit into this model. If you don't fit, there's something wrong with you. Um, as opposed to what might work for you, let's try and have a look at, you know, it didn't feel as though it was very tailor made." (Ruth, p. 21)*

> *"They don't have that specialised treatment, and I think it would save the NHS so much money, with people coming into hospital like five, six, seven months. I mean that must cost a fortune." (Janet, p. 22)*

Both Ruth and Janet describe what sounds like a blanket approach to their daughter's care. Ruth suggests that her daughter was being blamed for the inefficacy of her treatment. Janet then builds on this lack of "specialised treatment", suggesting that she does not feel that the NHS is using its resources effectively. I got the sense that she felt the "five, six, seven months" some spent in hospital were avoidable.

Ruth tried to tell professionals that their approach was not going to work for her daughter:

> *"To be told that when I said, you know, I know my child, and this approach is not going to, it's not going to work, to be then told that it works for most people, and therefore, I must give it a go because I was wrong, ha!" (Ruth, p. 20)*

Ruth's warnings were dismissed. This would have delayed effective care, allowing Holly's AN to cement further. Ruth's "ha!" coveys perhaps a sense of satisfaction or irony for being proved right, or sheer shock that they had the audacity to tell her she "was wrong".

Sarah too knew the standard treatment offered would not be right for her daughter:

> *"My daughter's on the ASD spectrum, and therefore someone asking her how she feels is not [going to work], and you know […] being able to offer, I mean well, I'm on the acupuncture*

> *thing now, but that being able to offer alternative therapies, alternative ways of recovering, that would have been amazing." (Sarah, p. 27)*

One set treatment may work for most, but Sarah knew that Chloe's ASD meant this would not be the case, and there ended the treatment options on the NHS. Sarah's suggestion of alternatives appears to reflect her disappointment, and desire for an improved service.

Sally also expressed little hope for Daisy's co-morbidities to be addressed:

> *"I'm not sure where, they, when they finish with what they think the eating disorder is, whether they're going to offer my daughter anything for anxiety, which she obviously suffers from, so co-morbidities I didn't hold much hope, other than perhaps being shoved on a massively long waiting list." (Sally, p. 25)*

This further highlights the lack of holistic care offered. Again the word "shoved" builds on the previous sense of participants feeling like their daughters are treated more like objects than patients. Sally too conveys her frustration regarding the accessibility of care.

3.2.3 Not ill enough

Multiple participants shared their experience of being denied care because their daughter was not considered unwell enough to receive it. Janet shared her disdain:

> *"It's been diabolical, it really has. I mean having to fight for your child, for you know, for your child to get support, to get your MP involved, because you can't get help. And they say, sorry, you don't meet the criteria. But if you got to a point where your BMI was so low you're just about to be admitted into hospital, we'll help you then. And then they only help you for a short time, because you're so ill you're put into hospital. So, awful, awful." (Janet, p. 23)*

Janet describes an unforgiveable process, that sees help withheld until the AN is life threatening. The lengths Janet describes going to, to get the help she wanted for her daughter shows her ongoing desperation, and exasperation she feels towards healthcare.

Claire shared her view on this. When trying to get her daughter into a hospital:

> *"She wasn't ill enough. She was probably on the verge a bit, but in England, she wouldn't have, she would have had to have probably even lost more weight. She was probably on the verge of it, but, but by then we'd disconnected with the NHS." (Claire, p. 24)*

This reflects a time when Claire was considering private hospitalisation in the UK, or abroad, providing insight into Claire's expectation that in the NHS her daughter would not have been considered of low enough weight, despite being "on the verge".

Interestingly, Sarah also experienced this with her son, who tried to get support during his sister's illness:

> *"My son had a very similar experience, he went and had a letter saying, yeah, we can't help you, and he said, it's because I told them I didn't want, I wasn't about to kill myself. That's what he felt. He felt because he wasn't critical." (Sarah, p. 29)*

This suggests a problem that is organisation-wide, not only leaving the sufferer feeling let down and unsupported, but the carer and wider family too.

Sarah and Janet also experienced this, however rather than their daughters not being ill enough to get accepted into a service, instead, they were discharged too early:

> *"So they discharged her when she was 17 because she'd reached a healthy weight, and wasn't responding to talking therapy, which I was absolutely livid about. I was furious. Um because I knew that she wasn't better, she just managed to get to a healthy weight." (Sarah, p. 8)*

> *"She came out of hospital, she'd only put um, I think it was only about four or five kilos on, she, she was still extremely underweight. She was still in danger. You know, and the consultant had given a target weight, and she was nowhere near that target weight, and they discharged her after five weeks!" (Janet, p. 17)*

Both express disbelief and anger at what they deemed a wholly premature discharge. For Sarah recovery is more than just reaching "a healthy weight", and therefore felt "furious" that that was the justification for her daughter's discharge. Janet's daughter, did not even appear to reach her target weight, and Janet’s heightened, almost frantic tone conveys a sense of shock and utter disbelief that this happened, leading to a heightened risk of relapse.

3.2.4 “There is not a lot of help out there, and you’ve got to find the resources yourself”

All parents reported left feeling alone and unsupported by health professionals, with many seeking support and training themselves to help them take on the role of carer. Sally described how she felt in those first couple of months:

> *"We had a brief six week kind of information session… I got all the books, and I read some of them, and they never, they never really said, what it comes down to is as parents, you've got to do all the heavy lifting here, they didn't say, the timescale for this illness, they kept saying 'oh it's a marathon not a sprint', but what does that mean?" (Sally, p. 23)*

It appears Sally felt she was allowed to enter into this blindly, receiving no warning from professionals about the amount, and duration of carer responsibilities. It sounds like of all the information she learned during those six weeks, what would have been most helpful was a clear presentation or at least an idea, of what lay ahead. Perhaps she feels she could have prepared herself better had she known. “What does this mean?” suggests she was sometimes left feeling more confused after receiving their guidance than before, later sharing a moment of realisation:

> *“There was me, learning about the illness and thinking well hang on a minute, you know, we've got years of this!” (Sally, p. 23)*

This shows how it was only through her own research that she discovered the true time frame of AN, conveying the shock she felt at this discovery.

In the following comment, Janet hints at a lack of NHS funding which could explain why Sally was not provided with the support necessary, and Janet realised that solely relying on professionals for her daughter’s care was not going to be enough:

> *"I know a lot of it is down to funding […]I just thought to myself, they're not going to help. They're not going to help. So I've got to take this role on. I've got to take this role on, because they're not going to do it." (Janet, p. 19).*

This illustrates how vital Janet felt it was that she took things into her own hands, and the repetition may reflect her coming to terms with the fact that her daughter’s recovery, was now her responsibility. She shared a message for other parents in her position:

> *"I just think it's for people to be aware that there's not a lot of help out there, and you've got to find the resources yourself. If you want them to get better, don't wait around, get the training. You know, even though you've lived it, you've still got to do the training." (Janet, p. 27)*

A warning that Ruth perhaps would have benefitted from hearing:

> *"I kind of thought this was the, they were going to help! Uh, and that, you know that, here were the experts. Um, that was not my experience." (Ruth, p. 20)*

Ruth’s sadness and disappointment is captured, revealing how her hopes of support for her and her daughter were dashed. Her voice tailed off towards the end, her tone becoming more sombre.

Claire however, knew this only too well:

> *"I was up all night reading any book, any literature, trying to get help." (Claire, p. 11).*

The sentence suggests that Claire was reading anything and everything in a desperate bid to make this easier, regardless of how this loss of sleep might impact her well-being.

Sarah echoed this:

> *"I, I wanted more than anything, I wish that CAMHS had been able to (help with the burden)" (Sarah, p. 27)*

Wanting help “more than anything” likely reflects Sarah’s feelings of desperation. She implies that she was utterly drained, and in dire need of something or someone to alleviate the distress and heavy responsibility she was feeling.

3.2.5 A poor standard of care – “It is just not good enough.”

The previous sub-theme suggested that mothers needed to take on a very active role as carers, seemingly doing professionals work at times, because they could not rely on the care provided. This sub-theme sees participants share their poor experiences of care.

Sarah reflected on a time she received an unhelpful comment:

> *"It was the most appalling experience either of us had had, at one point, the, nurse said to Chloe, […] 'what would you do if your mum was run over by a bus tomorrow?'.. Sorry? Did you really say that? I, absolutely. I could not believe that a healthcare, a mental health professional could say that to someone who was damaged and vulnerable. I mean, it was just extraordinary." (Sarah, p. 29)*

Sarah's words portray sheer astonishment at hearing this, perhaps describing a moment where Sarah discovered that MH professionals could in fact make things *worse.* This may have ignited a fear in Sarah, but certainly conveys why she may have stopped trusting professionals ability to provide effective care. Later in the interview, Sarah told me that she was "going to write a book about how healthcare professionals can't deal with mental health" (P. 29), and described care overall as "just not good enough", a sentiment shared by Sally:

> *"I've learnt the full story by reading myself, but then I'm, that's me, but if you didn't do all of that and just listened to what they said, I think you'd be doing your child a disservice, and you would hold your child back from having, standing any chance of really getting better, if you just did what they said. Isn't that terrible? *scoffs*. (Sally, p. 25)*

This stood out, making a real impact on me at the time of hearing it. How awfully sad to feel that if you left your daughter's care to the professionals, it is unlikely that they would ever recover fully, and you would perhaps be failing them in some way. "Isn't that terrible?" followed by a scoff, almost felt rhetoric, that perhaps she could not believe that is how she feels, or, maybe it was the first time she shared that belief out loud, and felt almost guilty for telling me, but that was the truth.

Claire described a couple of times she was let down:

> *"The counsellor rang me afterwards and said, she's alright, you've caught her early enough. She's not, I don't think she's anorexic. And I said, I'll be pleased if you're right, but all the signs are there. She's really not eating, which is, you know, and, and within four weeks, that*

> *woman was ringing me to say, you're right, she's terrible. I don't know how to cope with her." (Claire, p. 5)*

This captures how after initially being met with gentle dismissal, and reassurance that it would not escalate, Claire quickly received a phone call from the counsellor, correcting her previous misjudgement, and expressing an inability to treat Lilly any further. This shows the importance of listening to mothers, as Lilly lost four critical weeks of care, and once again, Claire was back to the beginning, in need of someone more qualified and able to help.

> *"The counsellor couldn't write to me, but had written to the GP to say she shouldn't travel. She wasn't well enough. But, of course they, they don't tell me. [...] when I said I'm now going to have to pick my daughter up, oh 'well didn't you know, did you let her go then?' And I said well [...] What could I do! Nobody had given me a letter, she'd told me it was alright " (Claire, p. 6 & p. 27)*

This depicts how a lack of communication with Claire meant Lilly's condition escalated dangerously. Lilly went abroad, only for Claire to later find out that "she shouldn't travel". Lilly ended up being airlifted off a mountain, and remained in a clinic abroad for "a good nine months" (p. 7). "Did you let her go then?" perhaps caused Claire significant levels of frustration, as the phrasing suggests it was an informed decision, which was not the case. Claire exclaiming "what could I do!" appears to further demonstrate how powerless she felt when faced with her daughter leaving, and that perhaps if she had received information about the wellbeing of Lilly, she would have been able to prevent her leaving, and subsequent health deterioration. I wonder whether this knowledge haunts Claire.

Helen described how even helpful experiences were tainted:

> *"This doctor in London, yeah that was a good experience in that we kind of got what we wanted. Oh, it was actually, *laughs*, it was quite funny. [...] He said some really unhelpful things, *laughing*, when we went to see him. I think it, I think it was um, about her weight or something he said, he commented on her weight I think, and said something that really wasn't helpful. It was like oh, you know, you're probably slim like your mum anyway. Which shouldn't just really, didn't help. Um, he just said, I think you just need to eat a few mars bars or something. Um, so he was, you know, *laughing*, not very helpful." (Helen, p. 29)*

I was struck by how much Helen laughed here. Yes, it was a positive experience as they “got what we wanted” (antidepressants for Maddie); however the flippant, throwaway comments regarding something so serious comes across as shocking. Why did Helen find this “quite funny”? Helen had previously told me that this was their family doctor, and that she considered him “an amazing man” (p. 29), so perhaps their pre-existing relationship meant she did not feel she could say anything negative. This was described as unhelpful for Helen however, but perhaps this was in fact as good as experiences with health professionals got for them.

3.2.6 It was not all negative

Despite the previous sub-themes exposing a high number of poor experiences with the healthcare system, it is important to note that there were a handful of positive moments shared. Sarah remarked on her brilliant GP:

> *"The GP was brilliant. Signposted immediately, understood what was going on. Absolutely brilliant. We were, we were very lucky, because I know some people have gone and gotten away." (Sarah, p. 28)*

Sarah is able to appreciate how quickly her GP took action, and understood how important it was to do so. She expressed her gratitude, knowing this is not the case for everyone.

Ruth also had positive things to say about her GP:

> *"Well, our GP and the nurse are outstanding. Um, but of course, it's not their expertise. And so automatically, they referred us to CAMHS for the eating disorder team" (Ruth, p. 20)*

This seems to illustrate exceptional care from their nurse and GP, however this was short lived, with Ruth’s shift in tone suggesting it was a shame when the time came for them to refer them to CAMHS, as things only got worse from there.

Despite the disappointment expressed by all participants regarding CAMHS, Sarah was able to acknowledge how they helped:

> *"CAMHS, you know, ok, it's great that we've got the clinic close by, and they took her, they*

> *took her on, and they, yeah, they did help her get to a healthy weight. So, so I can, you know, again, I won't fault that." (Sarah, p. 28)*

I sensed a reluctance when Sarah was talking, almost feeling like a “but” was to follow at any moment, but it appears to have been important for her to acknowledge that it was not all disastrous, and that they did help her in getting Chloe to a healthy weight, something she perhaps would not have been able to do without them.

Janet shared her positive moment:

> *"When we did have some help, that made me cope better, because you did have a consultant, she was listening to the consultant, we did have a good doctor." (Janet, p. 17)*

Hannah listened to the consultant, which helped Janet cope, capturing how important it is to have competent professionals around you: it is not just for the daughter suffering with AN, but for the carer too.

3.3 Group Experiential Theme 3: A heavy emotional, cognitive and physical toll

3.3.1 Mother’s physical and mental health suffered

All participants shared that their mental and physical health had been significantly impacted by the carer role. There were an overwhelming number of quotes initially extracted for analysis, and narrowing them down for this chapter was difficult, but I hope to convey enough of what participants experienced, not only the emotional and physical toll, but the profound cognitive burden endured in balancing their own well-being with their daughter’s needs, and how this affected them.

Sally revealed her struggles with depression:

> *"It, it's led to me becoming depressed, and I have suffered from depression in the past, so I guess I'm not surprised that that's what's happened. Um, it's it's I feel like it's sucked all the life out of me, but then that's depression does that so." (Sally, p. 15)*

This shows how low Sally became, and therefore how taxing the role can be on a person. Sally seemingly believes the role to be so challenging that if you have a history or predisposition for depression, then developing it is inevitable. Feeling like “it’s sucked all the life out of me”, implies profound feelings of emptiness, depletion and perhaps numbness.

Sarah’s experience mirrored this:

> *"I was very low mood, um I was very depressed, and I, I have a tendency to that. So kind of just all you know, kicked that off. Without my friends, without healthy relationships around me, um and I felt this was, there were times when I felt there was no hope. […] There were some very dark, very dark periods, there was a lot of crying going on, a lot of um, just helplessness that I felt, that I knew, that I couldn't do, I couldn't do anything"* (Sarah, p. 22)

Again Sarah is seemingly describing her depression as something lying dormant, then triggered by the ongoing challenges of the role. She also appears to suggest that the combination of the depression, isolation, and feelings of powerlessness resulted in a hopeless state. I note that Sarah describes not having any “healthy relationships” around her, perhaps showing that not only were her relationships affected, but that all familial relationships were infected by their daughter’s AN, including marital, sibling, and father/daughter.

Janet relayed the impact her daughter being in a psychiatric ward had on her:

> *"She wanted to come home but the amount of arguments there were over the phone and the Facetime, were, you know, it was very very distressing. She'd sometimes have her phone when the nurses came in and you could hear the nurses trying to hold her down and give her stuff to calm her down, um and how it affects you mentally... it was very distressing. Um, I had to have time off work because I wasn't coping." (Janet, p. 12)*

The image painted here, of Janet being able to hear her daughter being physically restrained through the phone can only suggest how difficult that must have been.. It seems that Janet was no longer able to continue living her life normally as a result. At times, Janet even experienced suicidal feelings:

> *"It's, it makes you not want to be here, because you can't cope with it. And you're seeing the*

> *person you love the most, literally dying in front of you, um but but, you cannot make them better." (Janet, p. 14)*

Seeing Hannah become weaker and not being able to stop it, seemed to pushed Janet to the edge of her emotional capacity. It all got too much for Claire too:

> *"I am a good coper with stress. I'm used to stress and sorting things, but I was at, I was at breaking point." (Claire, p. 22)*

This suggests everything became so exceptionally taxing for Claire that it surpassed what she considered her usually high threshold for stress, seeing her reach "breaking point", indicating she had reached a level of psychological distress, at which she felt she could no longer cope, or endure anything further.

In the interview, Helen gradually became more upset, eventually asking if she could "have a minute". She returned after a short break, happy to continue, but it was apparent that despite her daughter no longer needing care, revisiting memories was upsetting, revealing the lasting impact those past experiences have. It perhaps provides a window into what her lived experience was like at the height of her daughters illness.

Sarah also disclosed for the first time something she did when it all got too much:

> *"I would be in complete bits, I wouldn't know what to do... I do remember once or twice I would come into my, I'd come into my room away from her, and I don't think I've ever told anyone this but I would, I would scratch my arm. I mean, it was kind of a form of self-harm, I suppose, but only with my nails, but I would literally, I had to do something to, to get, get this total, this frustration, and this, this anger, and this resentment out because she was being so unreasonable" (Sarah, p. 18)*

The frustration and emotional turmoil Sarah found herself in resulted in her engaging in a form of self-harm (SH) to cope. I felt it brave of her to share this with me, and I was grateful she felt she could disclose it. It alludes to great despair and an intensity of feelings that were almost bubbling over, with Sarah seemingly at a loss at how to handle them. An urgency is conveyed, almost as if she was going to explode, she "had to do something", ultimately causing her to resort to something physical to get it "out".

Ruth's health was affected too, but in a different way:

> *"It's affected my, it's affected my physical health quite considerably. It's, it's going down now, but my resting heartbeat went up to about, my resting heartbeat is normally between 72 and 74. And my resting heartbeat had gone up to between about 84 and 85, which meant that I must have been permanently stressed every single minute of the day." (Ruth, p. 15)*

Caregiving stress seemingly had a measurable, physical impact on Ruth, increasing her heart rate on a daily basis. Ruth appears to reflect on what that must have meant, only now recognising how stressful she must have found every single day.

Janet struggled with both the physical and emotional impact:

> *"It's, living with someone with an eating disorder is, is unbearable. And it makes you ill. It makes you ill, I've lost a lot of weight, um, I've become extremely anxious, I've become very low, um I've felt quite suicidal, and I'm actually in a crisis team, because you physically cannot cope. You physically cannot cope with what they do to themselves." (Janet, p. 14)*

This powerful comment evoked a feeling of sadness in me as she spoke. Her pain is palpable, and her account conveys that living with someone with an ED slowly infiltrates every part of your being. It suggests that watching someone you love do this "to themselves" cannot be witnessed long-term without becoming not only mentally but also physically ill themselves, needing others' support.

According to Sally, it is you or your daughter, and your daughter will always come first:

> *"It's like you've got to choose between yourself, or choose between, or choose your daughters health. Of course you're going to choose your daughters health, why wouldn't you?.... You know, well maybe it isn't as black and white as that, but it feels, it feels that black and white." (Sally, p. 21)*

3.3.2 Fearing for their daughter's life

The majority of participants described living with the terrifying fear that they were going to lose their daughter. Claire shared one of the more poignant moments with me:

> *"I, walked off and I remember ringing my secretary and bursting into tears and said she's going to die, I can't do anything. She's going to die. What am I going to do?" (Claire, p. 19)*

This conveys helplessness and fear. Demonstrating how close to losing Lilly Claire thought she could be. “What am I going to do?” perhaps expresses Claire’s desperation and frantic search for someone who could give her advice or simply help her face a heartbreaking reality. Living with this fear is likely to have been an exhausting experience.

It seemed to be the same for Helen:

> *"Small goals were what kept me going, was achieving. Um, just keeping her alive really, just keeping her, her going. And yeah, it was a very, very difficult time." (Helen, p. 16)*

The paradoxical nature of Helen’s “small goal” of *just* “keeping her alive”, caught my attention. Although these daily achievements are depicted as modest, the reality of what those goals were for was monumental, and something that Helen had to carry every single day.

Ruth also described living in constant terror that she could lose her daughter at any moment:

> *"When my mother died, she was very, very suicidal. Um, and, and so I really, I would wake up in the middle of the night, terrified that she'd either self-harmed, attempted suicide or that her heart had stopped beating. Um, and that was it was very difficult to live with. But it was also very difficult to share because how can you explain that to someone else?" (Ruth, p. 12)*

It seems Ruth was alone in her fear, unable to turn to anyone for support for fear of lack of understanding. How could she possibly convey the terror of waking up in the night, petrified that her daughter had harmed herself, taken her own life, or died from anorexia triggered organ failure? This is a confronting, yet clear depiction of how emotionally and physically draining it was for Ruth to live through this experience, constantly facing the terrifying possibility that she would wake up and her daughter would be gone.

Sally revealed the potential long-terms effects carers are at risk of:

> *"They say that the parents do suffer from post-traumatic stress from having a child, and I'm you know, having sat there, with my daughter's heart rate being, you know, and being told*

> *that she must not exercise at all, because she might have heart failure, is yeah, that that's obviously left its mark." (Sally, p. 29)*

Sally suggests that she has been left with psychological scarring, and that perhaps it would not be surprising if she had PTSD, as it seems she has been unable to get over how close her daughter was to heart failure.

3.3.3 The burden of self-blame

Across all interviews existed a great sense of guilt and self-blame. Much of this appeared to stem from having AN themselves, and the fear that they had somehow passed this down to their daughters. Sarah shared her previous determination that this was not going to happen:

> *"I was always determined, as a mum having had an eating disorder, that my kids would not, I was just not going *laughs*, I was not going to let that happen." (Sarah, p. 7)*

Once Sarah's daughter became unwell however, she worried that she was responsible in some way:

> *"I know that I felt, I, I tried to fight against the feeling of guilt and responsibility that, that I had, that, that it was either my genes, which wasn't my fault, obviously, but, or what I've done something in her upbringing that had caused this" (Sarah, p. 21)*

It appears that Sarah had assumed responsibility early on to protect her children from developing an ED. As if it was perhaps her duty because of her history with the illness, therefore any development would likely stem from her. Her laughter almost seemed to be mocking her own naivety. Sarah later expresses recognition that if it were her genes, that is not her fault, but also that perhaps it was something she had done, conveying that she felt she could have done more to protect her. This sentiment was echoed by Ruth:

> *"I felt guilty. I felt somehow that it was my fault. Somehow, I, I should have protected her." (Ruth, p. 10)*

Sometimes Janet's guilt was exacerbated by comments from her daughter:

> *"You just think, and I know they talk about it being genetic and things like that, but I just think.. You think to yourself, a lot of the time she says to me, 'it's your fault. You shouldn't have had me, because you had me, I've got this.' Well I do blame myself sometimes that, she has this because of me, because I had it. But yeah, it's, it's awful, really."* (Janet, p. 15)

One might assume that for Janet to hear her daughter say "because you had me, I've got this", was incredibly painful, perhaps confirming an underlying fear, that this was in fact her fault. Her more softly spoken words "it's, it's awful, really", evoked the difficulty of living with this feeling of blame, from both herself and her daughter, and the real possibility that she inflicted this pain and suffering on Hannah.

Frustration and shame were felt by Helen when the genetic nature of the illness was implied:

> *"It used to really annoy me when someone said oh, it's hereditary. And I used to be really offended that, you know, just because I had it, I was kind of ashamed, that my daughter's might have it, I kind of felt a great shame that oh, God, you know, what have I brought to, what have I brought in to the family? Kind of thing." (Helen, p. 14)*

I found it interesting that initially Helen seemed to feel differently than the other mothers about this, displaying anger and offence at the suggestion, yet quickly it seemingly becomes apparent that detaching herself from this idea is a way to protect herself from the shame she feels at the thought of this being true. That she has in some way 'contaminated' the family.

Not all self-blame experienced stemmed from the onset of the illness however, some also shared they felt they were hampering their daughter's recovery, or even making them worse:

> *"My own anxiety and depression, that probably must play, play a part, and it that's there's this, I have a sense that, I'm hindering her recovery.."* (Sally, p. 28)

> *"The family therapists say, you know, is my, my anxious anxiety having too much influence over how I deal with the food element, so I have these big doubts in my mind, about my own approach and how it's failing my daughter. I do have that, a strong kind of, it's like an underlying niggle." (Sally, p. 27)*

Sally's daughter has been in stable recovery for a long time, but Sally is still actively involved in Daisy's care, and she describes her concerns that her own depression and anxiety are detrimentally impacting her daughter's recovery. Sally questions her ability, and whether she is "failing" her daughter, capturing the way she may be grappling with significant feelings of self-doubt, guilt and inadequacy, and perhaps see herself as the reason why her daughter is not getting better. The words "underlying niggle", indicates the persistence of this feeling. Sarah also expressed concern that she had in some way impeded her daughter's recovery:

> *"I've heard this from some people who told me, things that I've done have potentially not enabled her to be independent, because I have, um allowed her to kind of latch on to me. So I am very conscious of that, which is why I'm trying to separate us more now." (Sarah, p. 33)*

Sarah hints at multiple suggestions that in some way she may have stifled her daughter's independence, something she appears to want to rectify to avoid hindering Chloe's full recovery any further.

3.3.4 A heavy sense of responsibility

Mothers described bearing a responsibility to be what their daughters needed, providing them with the right care, and the weight of that. This was perfectly communicated by Sally:

> *"When your kid is little and something's gone wrong, they look to you to reassure them that it's ok, it will be fine, it's alright, you know you say those things, they need you to be like that, to make them feel secure, and I wonder whether when she's struggling with her food, and that frightens me, and I, I behave in a way that I'm also frightened, that she can't feel confident that it'll be ok. Does that make sense?" (Sally, p. 28)*

This shows Sally's fear that she is not being the mother she is meant to be. The quote suggests that mothers have a responsibility to reassure, comfort, and instil the security that everything "will be fine". It may also capture how visible Sally's fear is at times, something she worries feeds Daisy's AN further, illustrating how guilt and responsibility may interlink.

Sarah felt the pressure of being a mother too:

> *"I do believe, um as I'm sure many mums do, but I do believe that, I'm the person who can*

> *solve things that, that people need me to move on. So it was very much, I put myself in that position with her, and I did become her, you know, her, her carer." (Sarah, p. 13)*

Sarah appears to suggest that shouldering the sole responsibility to fix things, is felt universally by mothers, later describing how heavy this burden can weigh:

> *"In my, in my wildest dreams, I needed someone to come into the house, and take my face so that I could disappear.. I needed, and I know this is unrealistic, but I, I literally wished, I would have paid thousands,, *laughs*, for, I probably could have found someone if I paid thousands, but someone who she of course she'd have to relate to her, but someone who would come in and take my face and just take some of the, the burden just for a few hours." (Sarah, p. 27)*

This vivid description metaphorically underscores a profound sense of overwhelm, exhaustion, and desperation, perhaps capturing how Sarah fantasises about a life, or even just “a few hours”, without this responsibility, and the lengths she would go to get this. Wanting someone to take her “face”, so she could “disappear”, suggests not only a desire to be somewhere else, but to have someone temporarily assume her role, so she could be *someone* else, again highlighting an overwhelming sense of responsibility and need for emotional relief.

Claire was able to experience this when her daughter went away:

> *"It took all that weight off you. Yeah. You think about her occasionally, but you haven't got that day to day grind, that day to day, that knot in your stomach, that won't go away because you're thinking has she eaten her snack, how many times can she push that pea round her plate? *laughs* (Claire, p. 20)*

Claire’s description suggests how much lighter she felt when the everyday responsibility was removed, implying the constant, unrelenting nature of the support given.

3.3.5 It is all consuming

Four participants described the ways in which the role impacted their lives, as “all-consuming”; it took over absolutely everything, including their thoughts and way of living.

> *"Again, I'll go back to that phrase, 'all consuming'. To the point that everything else is shut out, and the problem is, with that, is that, that's the illness isn't it. The illness is all about food, 24/7, that's all someone with anorexia thinks about.... But it's become all I think about!" (Sally, p. 27)*

I found this to be a particularly poignant comment. Not only is Sally describing how the illness consumes you by shutting everything else out, but she appears to liken her experience to having the illness *itself*, as if she has been sucked into the anorexic world, without actually having active anorexia. Sally's change in intonation when telling me this was evocative of exasperation, distress, disbelief and perhaps even frustration that the illness had taken over her life the way it had. Sally repeated the phrase "all-consuming" several times during the interview.

It did not just take over Sally's life however:

> *"It really was, you know, you lived and breathed what was happening to Lilly. My son, he was not living at home, but he found it difficult. Um, so yeah, it did just completely take over, really." (Claire, p. 13)*

"Lived and breathed" conveys complete consumption, that Lilly's illness had become the central aspect of Claire's life.

Janet also described some of the ways her daughter's illness consumed her life:

> *"Well social life stopped, so I stopped going out with friends, I stopped doing things, because she was too ill to be left on her own." (Janet, p. 13)*

This reflects how all-encompassing the role became for Janet. Her responsibilities became her primary focus, taking precedence over her interactions with friends, perhaps revealing increasing feelings of isolation.

Even if something social was managed, Sally shared how this did not always provide the relief one might expect:

> *"When I was away with my friend, I was a little spaced out, 'cause I was just like, it was a*

> *bit shocking, I felt like I was in shock, to be removed from the home, and to have, I think it was 24 hours of just doing something for myself, just felt quite alien." (Sally, p. 18)*

This shows the extent to which Sally had become entrenched in the role, with it consuming her to the point where even a brief moment of respite, felt disorienting and unfamiliar. Feeling "in shock", might also suggest Sally felt numb, somewhat detached from reality, vulnerable, and overwhelmed. The reaction described may be an exposition of the profound impact that caring for Daisy had on Sally's sense of identity, and the psychological toll it took.

For Sarah however, space and time away from her daughter were a saving grace:

> *"She was away for two weeks. . . And it did absolutely, it was brilliant for me. I reconnected with friends. My husband and son were away on a holiday, and I literally, I just re-found myself, it was like respite, it really was it was incredible." (Sarah, p. 24)*

When Sarah was sharing this, the joy and relief she clearly felt at the time were almost tangible. It illustrates how much she appeared to have lost, her friends, her independence, her identity, and to re-connect with these parts of her facilitated a sense of healing and rejuvenation, that perhaps she had not had an opportunity to experience for a long time. This emotional transformation again emphasises the suffocating, all-consuming nature of the role, and the effect that it has on every aspect of one's being.

A final comment contributing to this sub-theme, but was only mentioned by one participant due to lifestyle differences, is the following from Claire:

> *"Luckily, you see if I'd had to, if I, if I, had had to hold a job down. I'm not sure how I would have held a job down. Yes, I could keep working but I could work you know, people could take, people had to make allowances for me because I'm the boss. I can't get sacked." (Claire, p. 20)*

Claire highlights the reality of the role, sharing her disbelief at the idea of anyone being able to work full time and care for their daughter. She appears to acknowledge her fortunate position, that enabled her to work and care, without either role being jeopardised.

3.3.6 The anorexia controlled the mother too

An interesting experience reported by multiple participants, was the feeling that they too were being controlled by their daughter's anorexia. Sally and Sarah gave the most detailed accounts:

> *"I'm telling her she's not allowed to compulsively exercise, but she's saying well you're not allowed to exercise if I'm not allowed to exercise. So it's that kind of, it's almost like it's controlling both of us, her illness, and I don't want to be controlled by her anorexia *laughs*." (Sally, p. 16)*

This depiction of Sally's daughter seeming to need her mother to conform to the behaviour she is adopting, shows how the illness can infiltrate the lives of those close by. Sally's words pertaining to not wanting to be "controlled by her anorexia", may suggest feelings of frustration and powerlessness, but, combined with the laughter that followed, a level of complexity emerges. Discussed previously as a possible coping mechanism for Sally, it may also express a sense of resignation to the absurdity of the situation she finds herself in, struggling to make sense of what is happening, and how it has got to this point. It may also capture Sally's desire to assert agency or independence, adopting a level of defiance against the control of AN.

Sally further told of having to exercise in secret, something that her husband did not have to consider:

> *"It's like she's put <u>me</u> under the microscope with eating, and exercise. Um so I find, I have to exercise in secret [...] It's weird, because my husband goes to the gym, and she doesn't have a problem with that. And that makes me angry." (Sally, p. 17)*

This portrays how closely Sally's behaviour was monitored by Daisy. Sally was put "under the microscope", resulting in secretive behaviour, perhaps mirroring that of Daisy's. The different rules enforced upon Sally and her husband, to which she reacted with anger and confusion, may point to some of the unique dynamics that arise between a daughter with AN and whoever becomes the PC.

Sarah shared how her daughter would dictate what she ate, and how that control was hard to shake:

> *"If we were out and I fancied chocolate cake or something, um, she didn't want me to have that, because it was very, too tempting for her, and she wasn't, it wasn't fair because she wasn't able to have it. I mean, I say all this, it's just horrendous when I when I say it, but this*

> *is how it was. So I would actually be, the eating disorder was controlling me. And I was restricting my food." (Sarah, p. 21)*

"I was restricting my food" feels poignant. The AN seemed to be controlling Sally in a way that meant at times, she was engaging in the primary symptom of the illness – food restriction. Whilst revisiting this, it seems that Sarah was realising for the first time how awful things had got, and how much of her own behaviour was dictated by AN.

3.4 Group Experiential Theme 4: A strained home and family life

This GET explores participants' experiences of significant changes in familial relationships and home life. All reported that both aspects were negatively impacted in some way, seeing different relationships tested and changes to family dynamics and behaviour. The feeling of being confined to the family home came across as especially prominent.

3.4.1 A family life in lockdown

Managing their daughter was not the only thing participants were having to contend with. Changes to mealtimes, and family life generally, appeared to spark feelings of frustration and helplessness. Sally likened their home life experience to the coronavirus lockdown:

> *"Our pandemic has just carried on…. Trapped, trapped, we're trapped. Absolutely, I feel like we're in a prison." (Sally, p. 18)*

Sally describes how there appeared to be no end to the pandemic for her and her family, no lifting of the restrictions on daily life. The family felt as if they could not leave their home or socialise with others, in or out of the house. Repetition of the word trapped intensifies the meaning, and her words "I feel like we're in a prison" convey a strong sense of entrapment.

Janet further built on the way that the AN exerted control over the whole family:

> *"So, it is, the eating disorder controls everyone, it doesn't just control the person that has it, it controls everyone that's in the family." (Janet, p. 12)*

A way it did this was through mealtimes, something that was revealed to be a significant challenge for families. Claire told me how structured and painfully drawn out mealtimes became:

> *"Mealtimes were very difficult." (Claire, p. 13)*

> *"Well mealtimes were, [...] say the time she was on her regime, three meals, three snacks, you know we'd do this sitting at the table, watching her push a pee round. You know, we could sit at that table for an hour, two hours, um, doing crosswords, doing all that, trying to chat about things." (Claire, p. 11)*

Claire shared how challenging eating became at home, describing how the experience changed their meals together, seeing them sit and watch her "push a pee round" for long periods, and often involving Claire and other members of the family incorporating distractions to help Lilly. This may capture how tiring and perhaps monotonous this aspect of home life became, particularly due to the number of times this was required each day, with each meal and snack almost rolling into the next. For Sarah, challenges around meals worsened, resulting in separation from the rest of the family:

> *"Gradually we got to a stage where I would, my husband would eat on his own, if my son wasn't there, I would eat with Chloe in the evenings. And the other meals were fairly sort of, you know, we had a structure" (Sarah, p. 14)*

This shows how Chloe's needs eventually meant Sarah was separated from the rest of her family at times, despite feeling locked in with them. This perhaps provides further insight into the previous sub-theme discussing how mothers find themselves 'in the illness' with their daughters, as it seems that Sarah was the only person that Chloe wanted around her.

Returning to her own experience of AN, Sarah later shared that for years there was "angst around mealtimes" and it was "a big effort" for her to "eat with other people" (p. 16), an experience echoed by Janet:

> *"You couldn't have people round when it was mealtimes. Um, you know, when it came up to birthdays or Christmas's that all had to be structured, like Christmas Day, we had, we had to plan hour by hour. So birthdays planned, everything had to be planned out. The day had to be planned out." (Janet, p. 10)*

This reveals how difficult it became for Janet and her family to socialise. Seeing friends or family over a meal, a common activity, appeared to become near impossible, with others not even being allowed in the house during mealtimes, and events such as Christmas and birthdays described as requiring meticulous planning and thought. This perhaps reflects a significant abnormality in the functioning of the family, and how draining trying to engage in a normal way of living had become for Janet. So, they stopped:

> "*Going to someone's house was really difficult. So we stopped having people over at mealtimes, and going into people's houses, or if we did go to relatives, we wouldn't eat there. Because it was too stressful." (Janet, p. 10)*

The same happened in Claire’s family:

> *"I could only do it with really close friends like Ellen, we still kept trying, but you couldn't have that casual bring people over for Sunday lunch. So we stopped. So that general family going out and, stopped a lot." (Claire, p. 16)*

Both examples reflect that entertaining socially as a family became so difficult that it was no longer worth doing; that perhaps it felt less tiring and painful to stop and accept that whilst their daughters were ill, this is how life was going to be at home. I notice that Claire continued to try with “really close friends”. This may have been because she felt freer of judgement, or perhaps merely a bid to hang onto a small shred of normality.

3.4.2 A complicated, challenging, and abnormal mother/daughter relationship – “It was like parenting a toddler”

As mentioned in the theme overview, the first and arguably most impactful change was that in the mother/daughter relationship. All mothers shared this experience, which included finding their daughter’s changing behaviour difficult to manage, increased conflict, a need for a change in parenting style, and an abnormal parenting experience overall, something that Sally likened to parenting a toddler:

> *"I have to be sure that my husband was coming back, not leaving too long a gap for her to be alone in the house, because she exercises secretly, um, and that yea, ... It's almost like having a toddler, where you, you have to make sure they're safe, you can't just go out when*

> *you've got a toddler, so it's a bit like that, and that's just not how I want to live my life, 'cause it's no life." (Sally, p. 9)*

Sally appears to convey her frustration at the regression in what is needed from her as a parent. The manner in which she said “because she exercises secretly” suggested sadness but also defeat, that there was always something else to consider or worry about, requiring more thought and more energy, evoking a subtle feeling of exhaustion.

Sally later said “the parenting is not like normal parenting, in terms of parenting a teen” (p. 16), and an example of what this might look like was presented by Helen:

> *"I would say things like, you know, Maddie, you just need to have a spoonful of rice, you need to have some sort of carb. Um, so, I would always make sure that those sort of key things were there for her to eat." (Beverley, p. 15)*

This demonstrates the constant encouragement and coaching Maddie needed from her mother to eat enough, like when you are trying to get a child to eat that one final spoonful before they are allowed to leave the table. This was not something typical of a mother/teenager relationship. Nor was the following:

> *"I also, do add extra oil to her food, which she doesn't know about. Um, just to make sure she's getting adequate fats, because, you know she's scared of fat." (Sally, p. 14)*

The secret increasing of calories and fat was a behaviour shared by a couple of the mothers, perhaps capturing how the secretive nature of AN can spread. Sally describing her daughter as being “scared of fat” also provides further insight into witnessing the illness in action, and the irrational beliefs that the mothers had to manage.

Sarah also felt the dynamic between herself and her daughter shift:

> *"It kind of consumed us and it became, it probably became um a bit co-dependent" [...] "It became very close. It became, very, um she became very dependent on me. Uh I suppose yeah, I kind of allowed that to happen." (Sarah, p. 13; p. 16)*

“Consumed us”, once again depicts how Sarah was seemingly sucked into the AN world alongside Chloe, with her suggestion of co-dependency perhaps indicating excessive reliance on Sarah but also an imbalance of power dynamics, with Sarah possibly prioritising Chloe's needs over her own, and a lack of boundaries between them. This could of course imply that Chloe needed her mother, but also perhaps that Sarah needed Chloe to need her in order to feel like she was helping, in a bid to retain some semblance of control. There is a sense of introspection in Sarah's final words, as if she was wondering what part she may have played in all of this, and if she could have done anything different.

Significant levels of conflict were also reported from the majority of participants, something Sally found shocking:

> *"She will swear at me, call me a tw*t, and a b**ch, and a d**khead, and I mean, God can you imagine speaking to your parents like that? I, yeah, I find it really shocking, um and again I find it hard to, deal with because I think well, it's because of the eating, and she's really into that at the moment, really calling me names." (Sally, p. 15)*

Sally shares how verbally abusive her daughter can become, despite being in stable recovery for so long, and how difficult that is to live through. The comment further reflects how Sally may not feel 'usual' discipline is an option as "it's because of the eating", perhaps further fuelling helplessness.

Sarah found herself growing resentful of her daughter's poor behaviour:

> *"There was that, resentment on my part towards her, for certainly for the, you know, wrecking my life in, in my worst moments. And um, just yeah, it was, it was really quite emotionally fraught, um a lot of the time" (Sarah, p. 14)*

I was struck by Sarah's phrase "wrecking my life", as it portrays profound emotional distress, perhaps involving anger, frustration, sorrow and a worry that the damage done is irreparable. "Fraught" was also used by Claire to describe life with her daughter:

> *"When you get really worried it gets more fractious and she's pushing you away because she knows you know, she knows she's not doing what she's supposed to. So it got fraught, fraught but still loving." (Claire, p. 16)*

This conveys how strained their relationship became, with a catalyst appearing to be Claire expressing concern, or interestingly, Lilly's own awareness that she was not behaving in alignment with recovery requirements. This illustrates elements of the role that may feel lose-lose, with Claire unable to find a way to care for her daughter without causing her further distress.

3.4.3 Witnessing the negative impact on husbands and siblings

Not only were all mothers impacted by their daughter's illness, participants also shared how they watched this happen to other family members too, notably fathers and siblings. Sally described how her husband struggled to manage their daughter's resistance to recovery:

> *"He finds it harder to be strong with her when she's pushing back, so and he sometimes, he kind of swings between kind of being sort of gentle with her, to completely losing his rag, and saying "just f***ing eat", you know *laughs*. .... It's fear. It is fear." (Sally, p. 12)*

This shows Sally's husband still struggles to find consistency in his responses to Daisy, flitting between a "sort of" gentle approach and angry outbursts. Sally laughing perhaps indicates embarrassment, but also a way to cope with the additional challenges she faces because of this. "It's fear. It is fear" however, shows that Sally may have reached a place of empathy and understanding towards her husband's unhelpful behaviour, perhaps helping her to forgive him and focus on the core problem at hand.

Helen's husband also found mealtimes particularly challenging:

> *"It was, um, a very difficult time for my husband. I mean eating you know, meals became quite stressful." (Helen, p. 16)*

Sarah's husband too was affected, in his case by Sarah and Chloe's close bond:

> *"I suppose because I'd been her, with her along the way, with food and everything, we became so interconnected, which I'm sure often happens, and my, my husband got pushed out because he didn't want to deal with it" (Sarah, p. 10)*

Sarah's husband appeared to experience isolation within the family due to not being Chloe's PC, and not wanting "to deal with it". I sensed two feelings from Sarah here, initially guilt, that perhaps her husband feeling separate from his family was because of her role in Chloe's care, and their resulting interconnectedness, but towards the end, quite the opposite. Something almost akin to indifference - he didn't want to be involved, so he isn't, and that is that. This could perhaps indicate a level of resignation and acceptance: his lack of engagement is something she did not have the capacity to change; pushing him further might even have been counterproductive, resulting only in inconsistent or unhelpful fatherly support.

It was not only husbands that were affected according to Sally:

> *"In the early days of re-feeding, which was so horrific, it was very distressing for her brother. And on the outside, it looked like someone's just refusing *laughs*. To him, he was just like, 'God you know, why is she doing this?' And he was so angry with her." (Sally, p. 11)*

This captures the difficulty Sally had with making this make sense to her son. Perhaps she was left wondering how she could begin to explain why his sister appeared to be “refusing” to eat. Her laughter perhaps echoing how ridiculous this may have appeared to him. She notes his distress, causing me to consider whether she had the capacity to attend to his anguish, something Sarah later answered:

> *"He resented the time I spent with her, and it, it meant he wasn't getting time, when he was at home, [...] he did show that, he did, rebel against that, and push against that, and um would express that to me, now and then and make me feel absolutely terrible, um, but it kind of spurred me on to try to pull away from Chloe" (Sarah, p. 19)*

This seems to capture how little room there was for anyone else, no matter how much Claire loved them. In Sarah’s case however, the deterioration in her relationship with her son, ultimately became a driving force behind trying to regain some independence.

3.4.4 Seeing the deterioration of the father/daughter relationship

This sub-theme builds on the previous, describing a further challenge that fathers faced, or perhaps caused, throughout the illness - the father/daughter dynamic, as seen through participants’ eyes. Helen describes a time when things were particularly bad between her husband and daughter:

> *"Her relationship with her dad was, was really bad then, um, you know, he just did not understand it, couldn't accept it, um would say all the wrong things. Um, and sort of sometimes be, “I don't care” you know, “I can't”, you know “it's ridiculous treading on eggshells”, “I can't say anything right”. Um, so I think that was really hard." (Helen, p. 19)*

It appears that Helen’s husband was unable to communicate with Maddie, due to a lack of understanding, and inability to accept what was happening. It sounds like Helen would watch him make things worse by saying “all the wrong things”, appearing then to be on the receiving end of his frustrations as a result, further adding to the stresses she was already carrying.

A similar experience was had by Sarah:

> *"Things at home were quite toxic between her and her dad, who didn't understand any of this at all. He'd been to some of the sessions with CAMHS, but he, he was very, very traditional and said well “just eat you know, we, we want you to just eat”, and he didn't give her the support and love that she was looking for from him." (Sarah, p. 9)*

Helen’s husband’s lack of understanding was mirrored here, with Sarah providing examples of what her own husband would say to their daughter, something I imagine was frustrating for Sarah to hear. I also note Sarah saying that he went to some of the CAMHS sessions, but that he was “very traditional”, prompting me to question whether she felt that his pre-existing beliefs overrode anything he may have learned in those sessions, and what she made of his apparent refusal to engage in new learnings that may have challenged what he had always believed to be true. I further wonder whether the love and support she wished for her daughter, reflected what she wished for herself.

Sarah later told me that things between them escalated to extreme levels:

> *"It got to a stage in the house where, and I almost can't believe this happened. She could not hear his footsteps, she couldn't hear his voice, she locked herself in her room. She couldn't have him around when she was, um we were making tea." (Sarah, p. 9)*

Sarah expresses pure disbelief at how bad things became between them, which might suggest a level of disconnection at and from that time. Claire also reflected on the deterioration of this relationship:

> *“So for a couple of years before her anorexia, their relationship got less close.....so it started to put a bit of a wedge in their relationship, and I think for the first few months of*

> *when she was poorly, because he didn't want to engage, wanted to pretend it wasn't happening, it probably got worse." (Claire, p. 14)*

This seems to reflect the importance for one to engage with their daughter's illness, if you hope to keep any kind of relationship with them, and therefore how alone with her daughter she may have felt in those first few months.

I found the following story from Helen thought provoking:

> *"Mike used to find it repulsive. Um, "she looks disgusting". "She looks, does she realise how awful she looks?" Um, you know, "what's her problem?" And I just said, well, you know, we're doing everything we can, we have these things lined up." (Helen, p. 17)*

As well as the harsh language used by Helen's husband, and how she may have felt hearing him call their own, vulnerable daughter "repulsive", this sparked another feeling. All comments in this section, and particularly this one, almost convey the sense that the mothers were in some way having to take their husbands on, to protect their daughters from their unhelpful behaviour or harmful comments. Sarah shared some experiences with her own father when she had had AN:

> *"My dad really didn't know how to, to deal with it. I'm really, I think you know the thing that's really, really interesting is the daughter father relationship, when with eating disorders, and there's some brilliant, there's some brilliant papers out there." (Sarah, p. 4)*

> *"I remember my father. He, at one, you know, he sat down with me one occasion, saying he was really concerned and "why couldn't I just eat?" And, and um, and interestingly, he was, he was part, part of the problem, well I think, part of the problem, parents always are aren't they really." (Sarah, p. 5)*

The parallels in experience are evident. Could Helen, or Sarah, and other mothers in this situation, be standing between their daughters and husbands, trying to prevent history repeating itself? Trying to stop their daughters experiencing what they did, and prevent husbands being "part of the problem", which in a way, protected them too. Being in this triangle perhaps created further responsibility, resulting in more anxiety, feeling on edge when their husbands came home from work for example, or when they would spend time alone with their daughter. This could be another reason why going out may have been more difficult, perhaps heightening the notion that the mother could not rely on anyone other than herself.

3.4.5 Husbands lack of understanding tested marriages

Five participants were married. Four described much of the behaviour reported in the previous sub-theme as significantly contributing to their marital relationship becoming strained. Claire found herself pushing her husband away once things got difficult:

> *"My husband and I have always had a very strong, good relationship. That got fraught because he, he's a man, he didn't want to know." (Claire, p. 9)*

> *"I found it very difficult, and I shut John out, you know, "well go and sleep in the spare room because I'm going to be up all night reading and I can't sleep", so we would probably spend more nights with him in the spare room." (Claire, p. 14)*

Despite a previously strong relationship, it seems the combination of Claire's husband's lack of interest and, contrastingly, how much Claire had to immerse herself in the illness and carer role, caused distance. Shutting him out, and telling him to "sleep in the spare room", may suggest underlying feelings of anger and disappointment, and a way of expressing these feelings without direct confrontation, which she may not have had the emotional capacity or energy for.

Helen expressed how her husband would take his frustration out on her:

> *"Mike, my husband is very much "got to fix this problem". "Let's throw everything at it". Um, it's very hard for a, a father to go through this and see his daughter, you know, "she just needs a f***ing steak", "why the hell doesn't" you know, and um, there was a lot of blame, he blamed me for not being on, in control of it, on top of it, and, and this is where my eating disorder kind, it came back." (Helen, p. 9)*

This appears to capture how difficult Helen's husband found the absence of clear and straight forward solutions. His outbursts and critical comments may reflect feelings of helplessness or frustration; casting blame onto Helen as perhaps an attempt to cope with that, and a way to deflect his own feelings of inadequacy. This behaviour seemed particularly hard for Helen to deal with, and subsequently triggered the return of her own AN, something discussed further in the following GET.

Loss of closeness and quality time was also deemed damaging to their relationship:

> *"We can't have any time together or, you know, we we're having to sort of do things separately so that someone is around, which is, which is fine, and that's you know, in a normal relationship that's quite healthy to do stuff separate, but the fact is we can't do anything really together, and I've, I've kind of lost motivation to do anything." (Sally, p. 21)*

The demanding nature of AN, and the need for someone to always be with Daisy, seem to have left Sally and her husband little space or opportunity to be a couple, something deemed important for a healthy relationship, and perhaps even more so when going through a particularly difficult time. Sally's loss of "motivation to do anything" however, suggests that if they were now presented with an opportunity to do something together, she would not want to, perhaps conveying that at this stage Sally feels drained, numb, and a shell of who she once was.

Sarah provides an insight into how much her marriage was tested:

> *"So certainly I'm not, I'm not quite sure how our marriage, my marriage has kind of survived this, but it has"* (Sarah, p. 19)

This turn of phrase gave the sense that this is nothing short of a miracle.

3.5 Group Experiential Theme 5: Mother's own AN experience – A double edged sword

All mothers referenced their own experience of AN in some way, and how this influenced aspects of their role or time as carer. Each GET thus far has revealed shared experiences, yet this theme presents a more varied account, with some sharing that their own experience was helpful while for others, not so much. For some, their own ED was also triggered by the role, with a few stating that it had never left in the first place.

3.5.1 Mother's own experience was helpful

Five mothers made notable reference to the way they felt their own experience of anorexia helped them, or improved their ability to care for their daughter. Much of this surrounded possessing a greater understanding of what their daughters were going through, which seemed to help both mother and daughter. Helen shared her experience:

> *"I think I was probably a bit more empathetic and a bit more understanding of it having been through it, I think it really.. Having been through an eating disorder myself, I think, I think it really helped. We picked it up early. The.. I understood, those feelings." (Helen, p. 19)*

Helen describes how as a result of her own AN, she felt able to truly know what her daughter was going through, and understand what she was feeling and how difficult it was. “We picked it up early” also conveys the idea that she had the ability to notice signs that perhaps would not have been visible to those without her history.

Having an increased understanding was a feeling shared by Janet:

> *"It was definitely easier, because I knew what she was thinking, and I could understand. I think sometimes, a person that hasn't had it, wouldn't understand someone saying, well I looked fat in this, when you know, they're so tiny, but I could relate to that, because you feel fat, you feel big, you feel uncomfortable." (Janet,* p, 25)

Through this improved understanding, Janet seemed to think that her own experience made a positive contribution to her caring role. In fact, her detailed description of what her daughter might be feeling suggests the role took her back to how she had felt when she was unwell, deepening her empathy. I got the sense that it was not difficult for her to put herself back in that moment, with the pain of that time almost feeling present again.

Claire echoed Helen and Janet’s comments, suggesting that perhaps a level of naivety accompanies those that have not had AN themselves:

> *"I knew how, how insidious it is how it's such, even though there's no reason for it, you should be perfectly alright, and you're not perfectly alright *laughs*. And I think probably if you're a mum without that, you could probably think, oh well, she's having treatment, it’ll be alright. It's like taking a pill, but I think I knew that it would be a long, hard slog, particularly once she didn't come.. once she kept losing the weight, I think for that first month." (Claire, p. 28)*

Claire suggests that without experiential knowledge you are left oblivious: more relaxed initially perhaps, yes, but oblivious to the complex nature of the illness, recovery, and how it is quite the opposite of just "taking a pill". However, thanks to her life experience, she thinks she already possessed this awareness and was therefore better able to face what lay ahead.

A further positive that arose was the benefit this brought to the mother/daughter relationship, with both Janet and Sarah sharing similar experiences:

> *"I think she knew I understood. I believed what she was saying. Um, and I think it helped that I had been through it. I don't think we would have had the relationship through the illness, if I hadn't had an eating disorder." (Janet, p. 27)*
>
> *"She knew about my, I think she knew about my eating disorder, and um, she kind of hid it, and confided in me because she knew that I would understand, which was actually quite an important thing for her." (Sarah, p. 7)*

Both quotes convey the idea that knowing their mothers would understand facilitated a level of trust and safety that meant the daughters were able to talk to them openly about what they were going through and how they were feeling. As Janet said "I believed what she was saying". This may also provide further insight into the interconnectedness and incredibly close – though not always healthy - relationship between mother and daughter that was repeatedly evoked here.

A poignant final comment from Helen, was that managing to recover from AN herself, kept her hope for her daughter alive:

> *"A fundamental belief that, some parents might think that this is never going to change, this is never going to get better. And to have faith that it will, is quite empowering. And that you can, you know, you can A; get over the eating disorder, and B; live a normal life like I have, was yeah, was pretty fundamental. And I truly believed, um, and I was able to say this to her, you know, you will be ok. You will get better. It's just a question of time." (Helen, p.* 32)

This demonstrates how Helen found strength from her own recovery, truly believing that her daughter's recovery was a 'when', not an 'if'. The words "belief" and "faith" bring to mind how one may rely on their religion in a similar way. Helen appears to have found strength by drawing on her own experiences to help guide Maddie through her recovery journey.

This sentiment was echoed by Sarah:

> *"Hope, patience, and the thought that it'll all come to an end, as it did for me" (Sarah, p. 34)*

This indicates the power of their own recovery, as the hope that it generates instils the strength needed to keep going.

3.5.2 With a greater understanding, came fear, collusion, and false hope

For some however, this greater understanding and insight into the illness was not always helpful, with numerous different challenges arising as a result. Within this sub-theme we see references to false hope, collusion, heightened fear, and frustration, with a comment from Claire selected to convey the first:

> *"It made me go into it, feeling confident that we would sort it because I'm, I'd been through it, I knew the pitfalls. I thought I'd found it really early, and I could talk sense into her. You know, I could tell her what happened to me, what, what I thought my triggers have been, how I got through it [...] but she had, she was, she went downhill much quicker because of doing all the exercise I think." (Claire, p. 27)*

Claire seemed to initially respond to the discovery of her daughters illness with great confidence, believing that not only had they detected it early, but she had the tools, knowledge and experience to “talk sense into her”, using what she had learned from her own experience, to inform a successful recovery process for her daughter. Although high confidence levels can be considered a powerful tool, this perhaps meant the fall to reality that this was not going to be something they could stop, was higher for Claire, and therefore hurt just that little bit more.

Sarah’s story was slightly different, seeing her reflect that her own experience resulted in an element of collusion and over-involvement:

> *"If I had no experience of it.....maybe I would have just insisted that we all sat down to eat, and that, um, you know, that I didn't try and manage everything in the way I did, sort of controlling everything, it would have just been.. ah I mean I think that's partly my character*

> *anyway, but things might have been different. [...] There was probably too much collusion on my part (Sarah, p. 31)*

This demonstrates Sarah considering how things could have been different, or what she could have done better if she had not had experience of the illness herself. She appears to question her significant need to control and manage, and the possible collusion she exhibited with her daughter's behaviour. The way Sarah thought through these feelings out loud seemed to convey a sense of "what if", as she seemingly tried to conjure up a different reality in which she had no history of the illness, and the subsequent improvement of care.

Claire described how her own experience of AN heightened her feelings of fear:

> *"When you realise what was happening, you're probably more scared because you know how it gets in your mind. Nobody else knows how it takes over and you can't think about anything else, and even then my life was good." (Claire, p. 27)*

As a mother, you typically want to do what you can to protect your daughter, with their health and happiness hailed as priority. So, when they develop AN, and you have lived with it yourself, and have experienced the suffering and symptoms first hand, the idea of them going through the same thing, unable to stop it, is likely terrifying - something Claire depicts here. Claire's own experience and knowledge seemingly inform her reactions, as she knows more than those who have not struggled about what challenges lie ahead, for both her and her daughter.

A final frustration that came from having had AN too was experienced by Ruth, and stemmed from the comparison of experiences:

> *"There's been a lot of frustration, uh, because once I decided to get better, I got better. Whereas, this has been a lot longer uh journey. Um, and Holly, has been talking about wanting to get better for a long time, and not been getting better. So, you know, I'm very much, a, you, you know, if you say you're going to do something you do it." (Ruth, p. 24)*

This portrays an interesting dynamic in the intergenerational experience, seeing Ruth becoming frustrated at the apparent slow nature of Holly's recovery. This felt surprising, as you might expect someone who understands AN, to acknowledge the idiosyncrasies of recovery, and therefore the uniqueness of her daughter's experience; yet it appears that Ruth is perhaps expecting her daughter to exhibit a similar level of agency and control. This may also express Ruth's feelings of overwhelm and helplessness regarding Holly's lack of progress.

3.5.3 Own anorexia was triggered, and came "creeping back in"

Four participants described how their own anorexia was triggered or began to creep back whilst caring for their daughter. This feels a particularly poignant theme in the context of the research question, and highlights that there is perhaps a risk to a carer's health in this position, if they have a history of AN themselves.

Helen noticed the return of disordered thoughts and behaviours:

> *"It definitely triggered lots of those feelings about it. I, I expect I started behaving a little bit like.. Um, so disorder, eating disorder habits, sort of, I would definitely try and skip a meal. If Maddie wasn't noticing. Um, I would definitely.. had in my mind that I had to be slim. um, yea, so, I definitely was triggered. Yeah. Yeah, and that manifested into sort of, eating disorder behaviour. Definitely." (Helen, p. 24)*

I noticed Helen struggled to present her experience clearly here, perhaps reflecting her confusion at the time, or how uncomfortable it is to acknowledge now. Her account describes both feelings and behaviours being triggered by the role, perhaps in a bid to cope, and how she began to engage in the secretive behaviours often associated with AN. This draws a complex image, of both mother and daughter hiding behaviours from each other simultaneously, perhaps suggesting the beginnings of a dysfunctional dynamic.

Janet experienced the return of her ED, but under the guise of trying to "remember how awful it is":

> *"You do sometimes have days when you don't eat, or overeat, because you're, it's like, I've had to do it to remind myself what it feels like. I sometimes forget how difficult it is living with an eating disorder. So some days, I've actually behaved as if I've got it, to try and remember how awful it is, for me to have a little bit of an understanding of how hard her day must be. Not very normal, but again, that's those behaviours coming back. Like I said earlier, they never go away, they never go away." (Janet, p. 16)*

Here Janet described days where she would under or overeat, but what was deemed particularly interesting, is that for the majority of the description, it appeared to be a conscious behaviour, aiming to help her empathise with how difficult her daughter’s days were. Janet seemingly corrects that however, revealing her understanding that it is really her ED creeping back in under false pretences. The repetition of “never go away” gives weight to this, perhaps emphasising the permanence of Janet’s AN.

Sarah builds on this, describing a time when she had to stop and question the nature of her increasingly restrictive behaviour:

> *"I was restricting my food and of course, there, there were at times when I would think to myself, you know, crikey, is this my eating disorder coming back, is this, you know, I was in a state of chaos, um something that I couldn't control, and this was, was I resorting to this um, by sort of indirectly." (Sarah, p. 21)*

Sarah’s realisation – “crikey, is this my eating disorder coming back”, appears to come after the food restriction had begun, which could perfectly capture the notion that AN sneaks up on you, catching you unawares. Sarah seems to hold an understanding that it was very much a coping mechanism for her, to help manage the “state of chaos” she found herself in.

Consequently, she endeavoured to remain vigilant:

> *"I kind of thought to myself, oh, are these the, are these thoughts coming back? So I was very, I was very conscious of it, and made sure that I kind of tried to know that they were potentially there, but not let them, not let them take over." (Sarah, p. 24)*

Janet also described trying not to let her thoughts win, but this time physical restraint was required:

> *"I've even called them (Beat), when I've had a difficult day, where I locked myself in my car, so I didn't binge." (Janet, p. 21)*

Janet had previously shared that at one stage, her anorexia developed into bulimia, appearing to have been triggered by the role. Janet describes locking herself in her car, and calling the helpline service Beat, conveying her desperation. Yet this was relayed to me in quite a matter of fact manner, perhaps signifying a level of detachment from that experience, or just that it had been a drop in the ocean given how difficult things had become at that stage.

A carer’s state of mind, and how they ‘left things’ with their AN, may impact the extent to which their AN can be triggered by the role. For example, Ruth’s unwavering commitment to never to restrict again appeared to ensure she was able to keep the thoughts that were triggered at bay:

> *"Oh I think certainly the thoughts (have been triggered) but, but as I say, because I've made this very conscious decision that I would never go back to that place ever again. I have been absolutely resolute about never restricting." (Ruth, p. 17)*

Janet expressed her shock at the power her AN still possessed after all this time:

> *"It's quite incredible to think, again it's controlling you again. Because you're allowing it to do this, you know, when I talk about it now, I think, how can I now allow that, but when you're in that moment, you just listen to that voice, it's like it comes back again. And it's 'I'm your friend. No one else is trying to help you through this difficult time. Just listen to me. I'll make it all better for you.' And you do. It's, it's, unbelievable, really, and powerful." (Janet, p. 16)*

Despite the time that had passed, and her efforts to help relieve her daughter of her own AN, Janet seemed powerless to stop AN returning for herself. Janet’s disbelief is evident here, almost unable to comprehend how the illness can return so suddenly and exert such power.

3.5.4 Recovered mothers enter the role with their own AN following closely behind – “I don’t think it ever goes away”

Something that became apparent throughout all interviews, when participants were describing their own experience of AN, was that it never fully leaves you. Although this may not overtly influence the care they provide, going into a role such as this, with an ED following, lingering in the shadows, waiting to be triggered, felt important to consider.

Helen shared how her anorexia has followed her over the years:

> *"It still surprises, it still, you know, it sort of weaves it's way in without me noticing, then I have to sort of get on top of it." (Helen, p. 12)*

This gives the impression that it tends to sneak up on her, rarely giving her an opportunity to nip it in the bud, only to manage and "get on top of" it. The AN still has an element of control over Helen, that she seems unable to tackle.

Pregnancy caused Janet's AN to disappear, but believes it never truly goes away:

> *"If I hadn't have fell pregnant, who knows if I would still have the habit now. I don't think it ever goes away though. I think you learn to manage it. I think, you manage it, because it goes away, but you still have those traits. You know, if you eat too much, you feel uncomfortable, um, even though you don't sort of have the behaviours, it is still there." (Janet, p. 3)*

This particular comment from Janet reminded me of the grieving process. You lose someone, it is painful, but life moves on. So, you learn to manage and grow around the grief. The sadness may no longer always be visible, but there will always be reminders, and it will always be with you. This evoked a feeling of permanence, and that a complete eradication of the illness may never be possible.

Sarah supported this:

> *"It kind of, it looms there a little bit, it kind of does say, you know, I could come back." (Sarah, p. 6)*

> *"It's really interesting talking about it, it's absolutely fine, but you know there are times when it sort of, you can, I can, I can just sense it, there in my past, it's so weird." (Sarah, p. 6)*

Something that struck me was that the AN was given a voice, "it does say.. I could come back", almost referring to it as its own being. Furthermore, the latter comment added almost a supernatural aspect to the AN, conceptualising it as the ghost of her past, that haunts her. Sarah states that "it's absolutely fine" to talk about, but I wonder whether there has ever been a sense of fear or anxiety over the years, that one day it might do more than just threaten to come back.

Ruth also described never being completely free from AN:

> *"I don't think if you've had anorexia, I'm not sure that you can ever entirely be free 100%? I'd say about 95% free?" (Ruth, p. 2)*

3.6 Group Experiential Theme 6: Caring for a daughter with AN – Surviving the role

Alongside evoking the challenging, and often isolating experience that is caring for your daughter with AN, all participants shared what helped them cope, and got them through such testing times. Types of aid included being supported by friends and colleagues; speaking to other carers; methods of support, whether professional or otherwise; and educating themselves as much as possible on the illness and how to manage it at home.

3.6.1 The vital role of work and friends

Friends, family and work proved to be vital sources of support and comfort during the most gruelling times when caring for a daughter with anorexia. Sally expressed how going to work helped her feel like more than a carer:

> *"Work makes me feel normal. And, I'm able to talk about things there, and it's me, me functioning on a level that isn't being judged, and I'm productive and I'm getting on with stuff. Whereas at home, that's really hard." (Sally, p. 20)*

This unveils more about Sally’s home life: home was not an environment conducive to functioning well; when there she could feel useless or failing, quite possibly leading to increased feelings of painful loneliness and isolation. Going to work therefore appeared to provide some crucial relief, enabling Sally to function as Sally, to feel useful, productive, and able to talk to others. It could indicate how freeing it must have felt, and perhaps how sad it was to have to go home. Ruth echoed this, describing work as her salvation:

> *"My dear friend whose daughter had anorexia. Um, she kept telling me to take time off work. And I'm saying but work’s the only safe place, I don’t want to take time off work *laughing*, you know, work has, has been my salvation. Um, because it's kept me going, and when everything felt unbelievably complicated at home, work felt straightforward. And I needed something where I wasn't going down, you know, I could thrive, and work was a place where I could thrive." (Ruth, p. 18)*

Again, the idea is that home was stifling, and that the workplace allowed Ruth to "thrive", providing an opportunity for her to engage in something that felt "straightforward" and safe.

Colleagues were not the only people participants reported being able to talk to. Helen shared the importance of remaining social, and speaking to friends:

> *"For me, it would be respite. […] you just need to chat with a girlfriend. Have a coffee, have a cup of tea, have a piece of cake. And it to me, it was a, a bit of a lifeline. That kind of thing. I would see that as rest." (Helen, p. 24)*

This seems to demonstrate that it was not always the act of speaking to friends that was beneficial to Helen's well-being, but just getting out, and experiencing that short relief, that "respite". The use of the word "lifeline" suggests that at times, socialising felt crucial to her survival.

Sarah was also fortunate enough to find support through her friends, and through getting away:

> *"Anytime that I could, could get myself away to either be just with me, or with my friends. That was huge help. My friends were hugely supportive all the way through, you know, even though we had a book club, not always about books, but we would get together every month or so, and, um, they were really, really supportive." (Sarah, p. 25)*

This further captures the importance of friends, and how their support helped Sarah through. I note Sarah's use of the words "anytime that I could get myself away", as this evokes feelings of entrapment, almost that she was being watched at all times, needing to find a gap in the surveillance to escape.

The significant impact familial support could have too, was articulated by Sally:

> *"If you know, I'd just had another blazing row about something, if he was sat in the lounge watching telly, I'd just go and sit in the lounge with him, and we'd have a conversation about something completely different, and it would make me think, oh, normal, you know, there is some normality there. This isn't my life, there is other life out there." (Sally, p. 20)*

Sally is referring to her son here, and it brings to life how brief moments with him at home, seemed to bring a sense of quiet, calm, and normality into an otherwise fraught environment. Sally stating that she was almost reminded in those moments that “there is other life out there”, further conveys how removed from reality she felt at times.

Helen became emotional when she shared how much she valued support from her parents:

> *"I had my mum and dad, um... they were really supportive *cries*, anyway and they were just, just there, they really were, they're amazing, nothing they could do they just, there was nothing they could do to help Maddie, but they were.. really supportive to me. I was their, you know, they were my sort of outlet." (Helen, p. 26)*

This again outlines how much these “outlets” meant to mothers in this position, and how despite not being able to do much practically to help, just being there was enough.

3.6.2 Speaking to other carers was a “lifeline”

Isolation was felt by most mothers, because despite how much others tried to support them, no one truly understood what they were going through, and therefore what they needed. When participants began to share the moment they first spoke to another carer, I could visibly see, before they said anything further, the life changing impact this had had. Helen suggested that other carers were more helpful than professionals:

> *"The biggest coping mechanism, of biggest impact was talking to other people that have been in that situation, same situation as me. And that was a lifeline." (Helen, p. 25)*

Stating that other carers had the biggest impact out of all the other help she received, suggests they really did provide the true meaning of a lifeline, with Helen later saying “this one mum completely changed everything” (p. 26). It conveys they were able to provide a kind of support that no one else was able to give, which Helen explained further:

> *"Well no one really understands, it's like anything, it's like cancer, it's like depression, it's like any you know, disease, *sniff*, no one really gets it until you've been there. No one really gets, you know, even having been through an eating disorder myself, it's different being a parent of someone with an eating disorder, no one can begin to say the right things, or give the right advice, unless you've really been there." (Helen, p. 27)*

I felt this to be an incredibly powerful message, that to a degree, speaks for itself and requires little interpretation. It reflects how even having had an ED yourself, is not enough to understand what you face in the role of carer, and until you find someone that knows, and sees what you do themselves, it seems that you are, really, completely on your own. Helen was holding back tears as she shared this with me, further amplifying the raw emotion connected to this, and how it felt to be supported by someone that could actually make things even just a fraction easier.

Sarah was fortunate to be able to find someone within her family that was able to give her this kind of support:

> *"My sister-in-law was a huge support. Um, she, my brother's wife, widow, um, my nephew had, has? Had? Anorexia, and used exercise, as many boys do, to, kind of control that. So she had experiences that she shared with me, and that's kind of, that was that was really, really helpful. Um, knowing that she knew what was going on. She'd been through it. And she gave me a lot of support, actually." (Sarah, p. 33)*

Ruth too shared her helpful experiences with other carers, who she was able to meet through online workshops and support group:

> *"There was a family liaison person that I was put in touch with, and she put me in touch with the Jenny Langley workshops, you familiar with it? Lifesaving. That that has been lifesaving for me. I don't think I would have coped without the support of her workshops, and you can once a month there's um, a parents support group and you just opt in." (Ruth, p. 15)*

More than one participant expressed their profound gratitude for Jenny Langley, and her work within The New Maudsley Carers. It seems the workshops and support groups can prove to be quite literally "lifesaving".

3.6.3 Alternative methods to keep you afloat

In addition to going through the typical route of a GP or NHS, and aside from finding help for their daughter, a few participants spoke about other things they had done or engaged with that made their role as carer a little more manageable. Sarah for example, spoke of several things that helped her cope:

> *"I wrote a lot of, I wrote a lot of journal, I did a lot of journaling." (Sarah, p. 21)*

Journaling has been known to feel like an extension of therapy, therefore perhaps it was a way for her to release her stream of consciousness, particularly if she did not feel there was anyone at home who she could speak to. Sarah did also utilise traditional therapy:

> *"The therapy I had obviously helped me deal with that [guilt and responsibility], so that I didn't, it didn't sort of, I wasn't submerged in that, and, and I didn't give myself too hard a time about it." (Sarah, p. 21)*

This shows how therapy perhaps enabled Sarah to keep her head above water when things got particularly challenging, providing her with the tools necessary to remove some level of guilt and responsibility, thus reducing the emotional weight she was likely carrying. Ruth also found therapy to be a helpful way to fill the space that she might have previously been filled by restriction:

> *"I've had a lot of therapy as well, I'd say, *laughs* I, I had some therapy at the time, and I've consistently had quite a significant amount of therapy for you know, the duration of my life. And so I've revisited when I've been vulnerable, I've sought help rather than self-medicating through control." (Ruth, p. 26)*

Sarah described the benefits of finding a physical therapy that worked for her:

> *"I've been doing, um following my own path in terms of learning about yoga, and Ayurveda, and that has changed me as a person to be so much more calm and patient." (Sarah, p. 18)*

This was not something mentioned by any other participant, but I was struck by the way Sarah felt it had "changed" her as a person. Sarah describing how it has meant she is now "more calm and patient" may suggest that if her daughter were to relapse or become more challenging, she would feel more in control, and able to manage that dynamic shift, without it impacting her to a similar extent emotionally.

Medication was something mentioned by Helen, as a method to stay mentally well:

> *"I've been on anti-depressants since I was um, um, since I was pregnant with Maddie, um, it manifested that I had major depression, and I'd sort of come down on my medication, and I immediately upped it again, just to help manage." (Beverley, p. 9)*

This refers to the time when Helen was concerned her AN was starting to creep back in, and home life was particularly difficult. We can see that anti-depressants are revealed as not being new to Helen. However they are presented as something she was able to reach for as soon as things started to become difficult, which perhaps took the edge off from that point onwards, giving her the strength to keep her head above water.

3.6.4 Learning, reading, and researching

The final sub-theme relates to participants taking it upon themselves to learn everything they could about AN and the carer role in a bid to help their daughter. The reason they felt they needed this additional care at home was of course outlined in GET two (sub-theme four), but here, three of the participants share how and why this helped them. For Claire, it was about feeling that she was doing everything she possibly could:

> *"I went to all their workshops I could. Read books, I just tried to think well, if I feel as though I'm doing everything I can, I'm giving her every support I can, there's nothing more, you know, in a way, there was nothing more I could do." (Claire, p. 22)*

This suggests that Claire was unable to rest, or accept the severity of Lilly's condition if she did not feel that she was doing everything in her power to help her. Only when she thought she had covered every base, every book, did she perhaps feel that another day could end.

Sarah shared her experiences of exploring the research and expanding her knowledge:

> *"I think those resources, and the resources that she (Jenny Langley) provides are, are just incredible. I've just literally tapped into some, she did something on bulimia and she sent through some resources on that because, you know we're, we're not completely out of the woods, and, and stuff, but she, so she was really, I found that really helpful. And some online, some online um accounts that I found. Just reading about, and hearing about other parents having, having difficulties, it really, that really helped." (Sarah, p. 26)*

When describing the resources sent by Jenny Langley, Sarah suggests they are not just standardised information sheets that are given to everyone, but “incredible” resources that she “tapped into”. This shows that not only did Sarah have the freedom to educate herself on what felt most needed for her family, but that she found that what was on offer was of a particularly high standard, and was truly informative and helpful.

Sarah and Helen reflected on their final learnings:

> *"I think, I think the biggest one of the biggest things that helped was understanding that I was a carer. So um, and that really put me on a different, a different sort of level, a different way of looking at things, and not so much as a parent.." (Sarah, p. 26)*

> *"The impact it had on me, it made me understand an eating disorder more than I ever did when I had one myself. Um, and it's the sort of journey that Maddie and I kind of went on together. And, um, we do talk about it a lot. You know, we laugh, and joke, but we do talk about it." (Helen, p. 20)*

These individual takeaways suggest that one of the most helpful things to learn about as a recovered anorexic carer, is yourself. What role you play, what is going to be required of you, who you are going to be in this process, and where you are in relation to you own illness. Sarah shared how being able to recognise and understand that she was now in fact a “carer”, shifted her position, changing how she approached her daughter’s care and future from then onwards. Then from Helen, something different: her learnings benefitted her the most in relation to understanding EDs as a whole, thus, more about her own experience. She describes this as a path she and her daughter Maddie went on together, creating a vital bond.

4 DISCUSSION

4.1 Introduction

Taking an interpretative stance, and striving to maintain a phenomenological psychological attitude throughout, the previous chapter aimed to shed light on how recovered anorexic mothers experienced caring for their anorexic daughters. This chapter will discuss the findings in the context of the existing literature. Consideration will then be given to the implications for clinical practice, followed by a critical evaluation of the study, presenting its strengths and methodological limitations. Suggestions for future research will then be discussed, before concluding.

4.2 Critical discussion of the findings

Table 3: *Summary of GETs and sub-themes*

Group Experiential Themes	**Sub-themes**
Watching the anorexia take over	Picking up on and managing the signs of anorexia was challenging "It was like she had been taken over by a religious cult" Witnessing their daughters' social disconnection A difficult journey to recovery and individuation
Healthcare – A broken system	Both mother and daughter were unable to get the support they needed A reductionist, one size fits all approach Not ill <u>enough</u> "There is not a lot of help out there, and you have got to find the resources yourself" A poor standard of care – "It is just not good enough" It was not all negative

Summary of GETs and sub-themes continued.

Group Experiential Themes	Sub-themes
A heavy emotional, cognitive and physical toll	Mother’s physical and mental health suffered Fearing for daughter’s life The burden of self-blame A heavy sense of responsibility It is all consuming The anorexia controlled the mother too
A strained home and family life	A family life in lockdown A complicated, challenging, and abnormal mother/daughter relationship – “It was like parenting a toddler” Witnessing the negative impact on husbands and siblings Seeing the deterioration of the father/daughter relationship Husbands lack of understanding and engagement tested marriages
Mother’s own AN experience – A double edged sword	Mother’s own experience was helpful With a greater understanding, came fear, collusion and false hope Own anorexia was triggered, and came “creeping back in” Recovered parents enter the carer role, with their own AN following closely behind – “I don’t think it ever goes away”
Caring for a daughter with AN – Surviving the role	The vital role of work and friends Speaking to other carers was a “lifeline” Alternative methods to keep you afloat Learning, reading, and researching

4.2.1 GET 1: Watching the anorexia take over

The first GET was comprised of four sub-themes, and provided crucial insight into the painful experiences of mothers having to watch their daughter’s anorexia emerge, take hold, and take over. The first sub-theme, captured the confronting initial detection of subtle behavioural changes, indicative of the secrecy and deception commonly associated with AN (Cottee-Lane et al., 2004), and their subsequent escalation, resulting in observable physical and personality changes. Consistent with the extant literature (e.g. Treasure et al., 2001; Smith et al., 2018), mothers in this study described observing clandestine behaviours including changed eating habits (e.g. disposing of food), and excessive exercise, resulting in feelings of shock, confusion, and deep concern. Participants spoke of their daughter's severe weight loss, decrease or complete cessation of self-care, and significant changes in temperament and behaviour towards them, such as aggression, and verbal abuse, with Claire recalling "meltdowns, frenzies" (p. 17). These fuelled pain and sadness in the mothers, and at times strong emotional responses which could lead to escalation. The distress caused by witnessing these changes is abundantly described in the existing literature (e.g. Ajulo, 2013; Treasure et al., 2001), with this study's findings therefore building upon existent knowledge. Additional research has also found regular interpersonal conflict at home to increase the likelihood of stress, depression, and anxiety in both carers and sufferers (e.g. Birdtt et al., 2017; Whitson & El-Sheikh, 2003), supporting the notion that it is vital for mothers/carers, with or without a history of AN, to receive ongoing support themselves.

Reports of distance, loss and powerlessness dominated the mothers accounts, as referenced in the second sub-theme. Mothers found themselves unable to halt the progression of the illness (e.g. Helen: "*I just could not stop it"),* or get through to their daughter (e.g. Helen: *"We just could not get hold of her… it wasn't Maddie").* Resonating with these narratives, much of the existing qualitative literature has conceptualised AN as assuming control over sufferers, disrupting their sense of self, agency, and connection (Tierney & Fox, 2011; Bruch, 1978). AN is often theorised as an entity in its own right, something that can be elucidated further by turning to the concept of the "anorexic voice", part of an internal dialogue that slowly becomes more dominant and self-critical (Treasure et al., 2020; Pugh 2017). A study exploring the lived experience of AN and relationship to the self (Williams & Reid, 2010), found the voice to split the sufferer from their authentic self, as it became increasingly controlling, almost 'demonic', whilst concomitantly providing a source of comfort and familiarity, resulting in an ambivalence to change. This may help to explain the disconnection participants felt from their daughters, and subsequent inability to break through the hold AN had over them (see also Serpell et al., 1999; Tierney & Fox, 2010). An interesting finding was that upon detection, some mothers believed that their own experience of AN would enable them to prevent or limit the escalation of the illness, continuing to grapple with disbelief when it didn't. There is thus some evidence that even former AN sufferers might benefit from caregiver psychoeducation.

The theme of powerlessness pervaded the entirety of GET 1, including the final two sub-themes. Building on previous literature about AN itself, and the carer experience (e.g. Fox et al., 2017; Treasure et al., 2001), participants reflected on bearing powerless witness as their daughter's lives unravelled around them, with rising concerns around social withdrawal, the impact on school life and academic performance, and overall social well-being, which further exacerbated their distress. Recovery itself brought limited relief: consistent with previous research (e.g. Kenny & Lewis, 2023; Dawson et al., 2014), with mothers describing the complex and protracted nature of the process, and their resulting frustration and exhaustion. At times, signs of compassion fatigue were noticed, reminiscent of secondary traumatic stress (Figley, 2002), revealing a further cost of the caregiver role. Here however, having personal experience of the process could be of help, as indicated by a comment from Ruth (p. 2): *"I had to relearn how to eat normally, and I can see that in my daughter".* This suggests that drawing on her own recovery experience helped her understand where her daughter was in her own recovery process, and be prepared for what was likely ahead of her, and therefore ahead of Ruth.

4.2.2 GET 2: Healthcare – A broken system

In a handful of accounts, participants shared positive experiences with healthcare, including quick responses and signposting from GPs, CAMHS aiding with successful weight gain, and good private professional support. Sadly however, overwhelming disappointment with the professional support they experienced dominated the narratives, particularly in relation to the NHS pathway and CAMHS treatment received. Six sub-themes were generated in relation to this GET: "*Healthcare – A broken system".*

All mothers shared their experiences of the many challenges they encountered when seeking support for their daughters, including long wait times, geographical barriers, and their daughters not being considered 'ill enough', echoing much of the existing research (e.g., Whitney et al., 2023; Krautter & Lock, 2004). Despite primary care often being the first port of call for parents (Keel & Brown, 2010), GPs and other primary care professionals were described as lacking in knowledge and dismissive, leading to misdiagnoses (*"I don't think she's anorexic"),* consistent with existing reports describing primary care as a 'barrier' or an 'obstacle' to care (Snilstveit et al., 2012: Keel & Brown, 2010). Mothers also faced considerable waiting times when referred on to specialised care with CAMHS, causing them frustration, even despair. Based on NHS reports, ED waiting lists currently pose a significant and growing problem within the healthcare system, and have done for some time (NHS Digital, 2020). Yet prolonged waiting times are associated with poorer clinical outcomes, an increased risk of relapse, and heightened psychological distress for both sufferer and carer (Kastner et al., 2021; Patel et al., 2018).

Due to previous growing concerns around waiting times and instances of what were deemed ‘avoidable deaths’ (Ayton et al., 2022), the NHS released the ‘Access and Waiting Time Standard for Children and Young People with an Eating Disorder’ in 2015 (National Collaborating Centre for Mental Health, 2015), in a bid to try and reduce the wait for those up to the age of 19, and began to invest substantially. Subsequent years brought a reduction, however the NICE approved 2020 target[12] has not been met. In the last seven years, EDs have more than doubled, and waiting times are again on the rise, with research and charity reports stating that some of those suffering are waiting months for NHS treatment, particularly if considered ‘non-urgent’ (Ayton et al., 2022; BEAT, 2019). This is supported by this study, with four of the six participants turning to private care at varying stages as a result, with Helen explaining: *“I needed something quicker than they could provide” (p. 28).* A couple of the participants that were financially able, expressed their gratitude for their financial privilege or private health insurance benefits.

Socio-economic status was not the only cause for the disparity in access to timely and appropriate care mentioned in the present study. Geographical constraints were also reported, in line with previous studies describing specialist treatment availability as a “post code lottery” (e.g., Mitrofan et al., 2019). The findings unfortunately highlight how some of the inequalities and systemic shortcomings present in British healthcare lead to increased carer burden (see also Robinson et al., 2020; Federici & Kaplan, 2008). It is also important to note that siblings, and the mothers themselves, were also affected by long waiting times when trying to get psychological support, leaving multiple family members in a state of deteriorating health, a finding that aligns with previous literature (e.g. Kopec-Schrader et al., 1993; Robinson et al., 2020).

Additionally, participants in the study saw clinicians’ use of BMI as a significant and dangerous barrier to treatment, as outlined in the sub-theme *‘Not ill enough’.* Janet and Claire for example, were met with the rhetoric of ‘she does not meet the criteria’ and ‘she’s not ill enough’ and were denied referral as their daughter’s health deteriorated. Claire’s daughter entered private hospitalisation abroad shortly after. Mothers also felt that support was only provided when a hospital bed was imminent. Conversely, premature discharge from treatment due to reaching a ‘healthy’ BMI left mothers feeling the treatment was incomplete, due to the lack of change in their

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[12] The target was that 95% of those referred would, for urgent cases, receive treatment within one week, and for non-urgent/routine cases, four weeks (NCCMH, 2015).

daughters emotional well-being despite their weight gain. According to prior research, these are all common experiences for carers, often leaving families without and/or fighting for professional support (e.g. Robinson et al., 2020; Mishra & Harrop, 2023). There is thus additional support for a shift towards a more holistic approach to AN treatment, in line with the biopsychosocial model (Treasure et al., 2021), and with research that found holistic treatment is preferred by AN patients (Smith et al., 2016).

Once finally granted, care was found to be overwhelmingly disappointing. In corroboration with earlier literature (e.g., Mitrofan et al., 2019; Robinson et al., 2020), participants reported a lack of communication and unhelpful comments such as *"what would you do if your mum was hit by a bus tomorrow?"* (NHS), or *"I think you just need to eat a few mars bars"* (private). As a result, many of the mothers ended up seeking out training, researching AN and learning how to be a carer in their own time. Resonating with the findings of past investigations (e.g. Sullivan, 2022), the standardised nature of CAMHS care was a particular source of distress (*"it's one size fits all"* - Sally (p. 24).

Knowing that CAMHS support abruptly ends at 18 left many mothers feeling they were *"on a race against time"* to get their daughter well, before being "chucked out" once they reached adulthood. These concerns around the transition to Adult Mental Health Services (ADMHS) are validated by existing qualitative literature, with mothers describing their experiences of the transition as "disruptive", a catalyst for relapse, and a particular period of stress for caregivers, while a report conducted by Beat (2017) stated that the adult waiting time was 176 weeks[13] (Robinson et al., 2020, p. 6; Gilsbach et al., 2024). Many have called for a change in approach that would adopt more of a continuum between services, including extending care up to 25, or an approach tailored to teenagers and young adults, something further discussed below.

Ultimately, the carers experiences of the NHS healthcare available were predominantly negative, with one mother concluding that if you solely relied on professional care, particularly NHS care *"you'd be doing your child a disservice".* Yet the challenges and unmet needs described here are no different to those expressed by caregivers over 15 years ago (Hillege et al., 2006; Highet et al., 2005; de la Rie et al., 2005), highlighting a dangerous, and persistent gap in the provision of care, and the desperate need for an improvement in these services to adequately support those in the caregiver role.

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[13] This is greater than the critical threshold of three years, after which the illness becomes more treatment resistant (Treasure & Russel, 2011)

4.2.3 GET 3: A heavy emotional, cognitive and physical toll

The physical and psychological impact this experience had on the mothers was an overarching theme throughout, as outlined in the six sub-themes within GET three. Participants described experiencing depression, anxiety, helplessness, isolation, suicidal thoughts, frustration, anger, powerlessness, loneliness, exhaustion, weight loss/gain, loss of physical fitness, and a prolonged increase in resting heart rate, indicating ongoing heightened stress. This provides support for much of the existing literature, which found the carer role to cause significant and lasting psychological distress and physical exhaustion (e.g. Zabala et al., 2009; Blondin et al., 2019). Sarah bravely shared that a couple of times she found herself scratching at her arm, in a bid to release the anger, frustration and resentment she was feeling, which upon reflection, she realised was a form of SH, attesting to the severe impact of her caring.

Some of the distress mothers experienced stemmed from constant fear that their daughters were going to die, and the sense that it was their responsibility to keep them alive. These were outlined in sub-themes two and four. This lends support to earlier findings, as a 2013 meta-synthesis of 20 qualitative studies of carers' experience found that concern around the possibility of their child dying was present in nine of them (Ajulo, 2013; see also Carpinelli et al., 2022). Extant research has also posited that trauma symptoms are prevalent in parents taking care of their children or young adult with a life threatening illness (Yagiela et al., 2019; Carmassi et al., 2019), even many years after successful treatment (Lindahl Norberg et al., 2012), echoing Sally's report that her daughter's previous risk of imminent heart failure had *"left its mark"* (p. 29). Timko et al's (2023) findings also found PTSD to be common in parents of those hospitalised with AN.

Carers of young people with AN often experiencing self-blame, drawing a link between the illness and their parenting practices or general upbringing, is well established (Whitney et al., 2005; Perkins et al., 2004). This is further corroborated in sub-theme three, which also reveals how mothers with a history of AN might experience heightened levels of guilt and self-blame, stemming from the fear that they have in some way, passed their illness on despite their determination upon having children, that they were *"not going to let that happen"* (Sarah, p. 7). Guilt could also be compounded by their child weaponising the possible inheritance of AN against their mother at times of conflict (e.g. *"it's your fault, because you had me, I've got this"* Sarah, p. 21). Research exploring the intergenerational transmission of psychopathology supports these findings: those with a family history of mental illness are prone to increased feelings of fear, guilt and responsibility regarding their child's well-being and any subsequent development of illness (Evenson et al., 2009;

see also Nicholson et al, 1998). Self-blame has also shown a positive correlation with heightened PTSD symptoms (in relation to carer trauma) and carer distress (Kingston et al., 2016; Fortune et al., 2005), which for some, has also been shown to hamper caregivers' ability to effectively care for their child (Kyriacou et al., 2008).

Finally, unwaveringly evident from participants' accounts was that the aforementioned distress was inescapable, as the role, and their daughter's illness, were all-consuming. Echoing earlier findings (e.g. Fox et al., 2017; Cottee-Lane et al., 2004), mothers described how all elements of day to day life were impacted, including their thoughts, behaviour, and social (and for some professional) life, with comments including *"it's become all I think* about!" (Sally, p. 27), and *"you lived and breathed what was happening"* (Claire, p. 13). The data further revealed that for some, the illness did not just consume them, but controlled them too, something that has perhaps been alluded to in previous literature, but not attended to in any depth. Through their daughter, the AN was able at times to dictate their behaviour, including how much they exercised and ate, leaving some feeling like they were under the control of AN too; *"the ED was controlling me, and I was restricting my food."* (Sarah, p. 21).

4.2.4 GET 4: A strained home and family life

In 2015, Eisler and colleagues (Eisler et al., 2015), proposed a theoretical framework suggesting that when caring for a child with AN, families become 'reorganised' around the illness. This was echoed in the fourth sub-theme, which captured the way mothers likened family life to the Covid-19 lockdown, describing feeling imprisoned in their own home, and the family system becoming generally dysfunctional, and spoke of seeing the AN assert control over all family members. In line with existing research (e.g. Whitney et al., 2005; Cottee-Lane et al., 2004), mealtimes were reported as being times of particular strain, often lasting for hours, and for some, resulting in the family eating separately to reduce conflict and distress for all parties, leading to increased feelings of separation and isolation for caregivers, who would continue to eat with their child. Research has shown family mealtimes to play a vital role in AN recovery, due to the importance of weight restoration and re-nourishment (NICE, 2017; Macdonald et al., 2014), and it has been suggested that outcomes are worse in adolescent AN if, post treatment, families do not eat together (Jaffa et al., 2002). This therefore highlights the complex and paradoxical nature of the caregiving environment, wherein the challenging realities of everyday care and dynamics, make ideal recovery practices seem impossible. A study conducted over 20 years ago, heard PCs specifically requesting increased mealtime support (Haigh & Treasure, 2003), and as this study shows, they continue to do so today. Not only were mothers and the family locked in, but others were locked out, with social activities sacrificed or meticulously structured due to how difficult mealtimes and life at home had become. Visiting or hosting friends or family, was no longer seen as an option because *"it was too stressful"* (Janet,. p. 10), resulting in a complete loss of normalcy for the mothers, a finding that builds upon extant research (e.g. Fox et al., 2017; Dimitropoulos et al., 2009).

In line with Eisler's framework, familial relationships were profoundly affected. As discussed in the second sub-theme, the mother/daughter relationship became significantly strained, with mothers describing not only increased conflict but also a need for a change in parenting style as they tried to manage secretive and abusive behaviours, fear around their daughter's safety if left alone, and having to encourage them to eat or hiding foods such as oil in their meals, which for some, at times, felt like *"having a toddler"* (Sally, p. 9). This echoes earlier findings reporting conflict, abnormal relational patterns, and co-dependency (e.g. Fowler, 2016; Goodier et al., 2014), the latter of which was also hinted at here, with Sarah stating *"I kind of allowed that to happen" (p. 16).* Mothers' unwitting entanglement in the AN through trying to help, and their subsequent loss of identity, is also present in previous literature, and has shown how this can feed the development of a problematic mother/daughter relationship, substantially increasing carer distress, all of which can ultimately contribute to maintaining the AN (Fowler, 2016; Rhodes et al., 2009). Several studies have found treatment that helps to reinstate boundaries to be vital in helping caregivers move away from a position of enmeshment (e.g. Goodier et al, 2014; Voriadaki et al., 2015), thus emphasising the importance of including this in caregiver training or support, particularly with this population, who are perhaps at greater risk of over-involvement due to the heightened sense of responsibility previously discussed.

Witnessing the impact of AN on fathers and siblings was also a distressing part of the experience for a number of the mothers, who reported brothers' distress, avoidance and frustration towards their sister, and tension and friction between mother and son, often stemming from resentment that there was now no time for siblings' needs. Similar findings have been reported in research exploring the impact on siblings (e.g. Cottee-Lane & Pistrange, 2004; Garley & Johnson, 1994). Furthermore, fathers/husbands were often described as struggling to understand and manage the illness, finding mealtimes particularly difficult, often being pushed out and becoming isolated. Additionally, descriptions of fathers' contributions and support throughout their daughter's illness were rarely positive. Mothers described a lack of understanding or desire to understand, a lack of acceptance, unhelpful and damaging comments, and frustration at the absence of a clear solution, all causing severe, and sometimes almost irreversible, strain on both the father/daughter and marital relationships. We know significantly less about the fatherly experience of caring for a child with AN. From the mother's perspective as they care alongside them, we know that some are able to approach the role collaboratively, often with the help of FBT, fostering a sense of teamwork (e.g. Stillar, 2018). However, research suggests that frustrations around husbands' inability to understand or engage in their child's recovery process are common, typically leaving mothers feeling like a single parent, alone in the role (Williams et al., 2020), something very much echoed in this study. Interestingly, and unique to this study, some participants referenced their own fathers' behaviour when they were unwell, citing similar disappointment: *"My dad didn't know how to, to deal with it", "he was part, part of the problem"* (Sarah, p.4 & p.5). Some studies have suggested that societal gender stereotypes; the way father/child attachment develops, a higher tolerance of child distress, but also different coping strategies for said distress, such as emotional withdrawal, may all play a role in perceived differences between maternal and paternal care. These, combined with ambiguity and limited role preparation, may contribute to reduced self-efficacy, and a reduced ability in fathers, to provide effective care when attempting to manage their child's AN (Affleck et al.., 1990; Lamb, 2010; Paquette, 2004). This points to a need for interventions to address parental gender differences, encouraging more active levels of involvement from fathers, to not only enhance the effectiveness of treatment, and lessen the caregiver burden, but to reduce additional caregiver trauma, such as the distressing strain on relationships, and the risk of separation or divorce.

Overall, these findings echo systemic ideas around the interrelatedness of family subsystems, illustrating how AN exerts a ripple effect across the family, reshaping boundaries, roles, and interactions (Minuchin et al., 1978). The strain described by participants also aligns with research highlighting the destabilising impact of chronic illness on family dynamics, with Goldenberg and Goldenberg (2013) noting that caregiving roles can lead to structural imbalances, as families reorganise themselves around the illness, often at the expense of other relationships within the family system (as seen in this study, fathers and siblings were frequently marginalised, and marital relationships were strained). This systemic perspective is critical to understanding the profound relational impact of AN, as well as the potential challenges in restoring healthy family functioning.

4.2.5 GET 5: Mother's own AN experience – A double edged sword

The fifth GET, *Mother's own AN experience – A double edged sword*, shed light on the unique challenges, advantages, perspectives and experiences that may arise from mother and daughter's shared history. As reported in the first sub-theme, participants told of how being able to draw on their own experience endowed them with greater empathy, understanding, and awareness of the potential severity of their daughters' AN; this facilitated earlier detection of the illness, benefitting the mother/daughter relationship, as daughters felt more able to be honest and open with their mothers, knowing that they would understand. This aligns with the small amount of existing research into the impact of lived experience on caregiving, which found that it enhanced insight and understanding (Greever-Rice et al., 2020).

Several mothers also described how their own successful recovery allowed them to remain hopeful for their daughters, fostering feelings of empowerment, patience, and *"a fundamental belief"* (Helen p. 32) everything was going to be ok. This may have contributed to creating a more supportive and optimistic caregiving environment, something research has found to improve MH outcomes in both carer and sufferer (Cheavens et al., 2006; Gallagher & Lopez, 2018).

Conversely, the same heightened understanding and empathy was not without its drawbacks, with mothers also experiencing false hope and confidence in their ability to halt the progress of the illness, and increased fear, as they were acutely aware of the potential pain and devastation that lay ahead for both themselves and their daughter. Moreover, a couple of mothers suggested that their own experience drove them to over-involvement, striving to manage, control, and collude with their daughter. In the context of caregiving, collusion often presents itself as an unintentional, dysfunctional coping strategy, typically stemming from profound feelings of guilt and fear (Bergquist, 2013) [14]. As previously discussed, mothers with a history of AN may be especially prone to feelings of responsibility and guilt, and thus at greater risk of collusion, despite the attendant risk of longer recovery times and poorer outcomes for their daughter. Mothers also cited increased levels of frustration when comparing their own recovery rate with their daughters: *"There's been a lot of frustration, uh, because once I decided to get better, I got better. Whereas, this has been a lot longer uh, journey."* (Ruth, p. 24). From a theoretical and clinical standpoint, this over-involvement and collusion could perhaps be explained by psychodynamic processes, where unconscious identification with the daughter, unresolved conflicts, or defences against anxiety complicate the mother's ability to establish healthy boundaries (Rutter, 2000). These dynamics can lead to a blurring of roles, where the mother becomes overly engaged in the daughter's struggles, potentially out of a need to protect or control. In the context of attachment theory, this over-involvement may also foster a dependent relationship, as the mothers may have unconsciously attempted to preserve the bond with their daughters at the expense of both their

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[14] Collusion can be defined as secret cooperation or agreement, often for an illegal or deceitful purpose, including maintaining harmful situations or behaviours - Merriam-Webster, n.d.

individual autonomies (Bowlby, 1988). These interwoven dynamics may contribute to the emergence and/or maintenance of a dysfunctional family system, and impede the daughter's recovery by reinforcing patterns of enmeshment and dependency.

The idea that "*AN never leaves you*" was outlined in the final sub-theme of GET 5, with one of them declaring: "*I don't think it ever goes away".* Multiple participants shared how AN had followed them over the years, unbeknownst to them, in line with previous literature (e.g. Conti, 2018; Neimeyer, 2000). Importantly here, four mothers described how their own AN had been triggered in some way because of the caregiver role. Anorexic thoughts (*"I.. had in my mind that I had to be slim"* Helen, p. 24*)*, and behaviours (such as meal skipping), were triggered due to the *"state of chaos"* (Sarah, p. 21) and stress they found themselves buried in, seemingly activating their old coping mechanism of AN, with one participant needing to call a helpline as she locked herself in her car to avoid engaging in disordered eating behaviours. Heightened anxiety, confusion and vigilance was also experienced, as they wondered if these behaviours were prompted by a recurrence of their AN. The complex and distressing nature of the caregiver role is extensively documented, but the current study builds on this existing knowledge, revealing that for those with historical personal experience of AN, these struggles can be compounded by the possible re-emergence of their own ED symptoms, calling attention to the truly unique needs of these mothers.

In the absence of literature specific to this phenomenon, it may be worth mentioning the various family aggregation studies that have discovered a genetic component in the onset of other psychological traits or illnesses, such as Obsessive Compulsive Disorder (7% - 15% prevalence rates in first degree relatives - Pauls, 2010), anxiety disorders (approximately 30% heritability - Gottschalk, 2017) , and alcoholism (50% genetic risk - Tawa et al., 2016), and which sought to compare caregiver experiences in the same way in the context of these illnesses, reporting similar feelings of guilt and shame. However, it seems that the absence of qualitative literature exploring the caregiving experience when both have received a diagnosis is not limited to AN, suggesting a wider research gap now requiring attention.

4.2.6 GET 6: Caring for a daughter with AN – Surviving the role

In light of the many challenges identified throughout the study, the final GET that emerged, detailing the various supportive factors mothers leant upon, was crucial in shedding light on what fed caregiver resilience and made this experience more bearable. The first sub-theme, showed how participants found solace in work and friends, perhaps due to the lack of formal support available to them. Work was seen by one as *"salvation"* (Ruth, p. 18), offering respite from the complexities of home life and reducing feelings of isolation. Furthermore, the ongoing support, and sense of normalcy, that friends and family provided was described as a *"lifeline"* (Helen, p. 24)*,* with interactions offering participants an opportunity for connection, calm, and a reminder of their identity outside of the caregiving role. These findings are consistent with various existing studies, emphasising the use of these support groups to aid with the emotional toll often taken by AN, including the erosion of personal identity (e.g Fox et al., 2017; Honey & Halse, 2006). Caregivers have also stressed the value of collaborative working and family unity (e.g,. Whitney et al., 2005), as has Szmukler et al's (1996) caregiving model.

Connecting with other carers was considered *"the biggest coping mechanism"* (Helen, p. 25) by many, as discussed in sub-theme two, as they possessed a level of understanding seldom matched elsewhere. Organisations and support groups such as Jenny Langley's workshops within the New Maudsley Carers were also valued highly for this reason, as being able to discuss and share experiences proved invaluable: *"I don't think I would have coped without the support of her workshops."* (Ruth, p. 15). This is in line with some previous findings (e.g. Beale et al., 2004), however not all, as some found that accessing groups could be difficult due to shame (e.g. Huke & Slade, 2006), once again highlighting the importance of targeting feelings of shame in caregiver support.

Moreover, various other coping mechanisms were employed by participants to help them navigate the role, including journaling, therapy, physical activity such as yoga, and anti-depressants, all facilitating improved well-being and reduced distress, and have been well documented as useful to ameliorate and/or mitigate future risk of psychological distress (e.g. Kim-Godwin et al., 2020; Bhandari, 2017). Moreover, the proactive pursuit of knowledge and understanding captured in the final sub-theme, helped mothers to garner a sense of increased control and understanding, not only about AN but also about their role in their daughters' recovery, with a couple of participants sharing how helpful it had been to realise they were in fact now a 'carer', not just a parent. Research has outlined how crucial improved knowledge can be when attempting to cope in a role such as this, with Mishel (1988) positing that a significant source of stress for caregivers can be that of uncertainty. Furthermore, it seems that those possessing a clear understanding of their responsibilities and role are better equipped to manage the task, as they are able to more clearly organise and align their efforts with the needs of the individual they are caring for (Farran et al., 1999). This perhaps could serve as a suggestion to prioritise the immediate dissemination of comprehensive educational resources to carers upon their child's diagnosis, perhaps especially important for this specific population, who in some cases have been shown to initially believe they are more knowledgeable than they are due to their own experience.

The study findings have provided several key contributions to the field. They add further support to existing work around the experience of witnessing the onset of anorexia in one's child, and how it subsequently takes over; predominantly negative experiences with healthcare services; and the adverse impact of AN on family members and familial dynamics, including the severe emotional toll on mothers as PCs. The novel contributions that have also emerged, offer unique insights into the experience of these mothers, highlighting some of the similarities and differences between them and other mother carers without experience of AN. Firstly, upon initial onset these mothers appear more likely to have faith in their ability to help prevent, or limit the escalation of the illness due to their own experience, something that can ultimately lead to false hope and further distress. However, drawing on their own experience of recovery also enabled them to better understand their child's experience, increasing empathy and awareness, helping them to prepare for what lay ahead, and offering increased hope to their daughter. A further original finding is that whilst self-blame is common within the caregiver experience, it seems heightened in this population, with some daughters even appearing to 'weaponise' their mothers' experience; exacerbated self-blame could then lead to over-involvement in their daughter's care. Another critical new insight was that for some, the role triggered their own AN, or sparked a re-emergence of ED symptoms (in one case leading to SH). Lastly, while prior research already suggested significant disparities in mothers' and fathers' involvement, it was noteworthy that participants in the study drew parallels to their experiences of their own father, confirming that this gender disparity of involvement and support in caregiving roles appears to be longstanding.

Caregiving mothers with a history of AN, and those without, share many common caregiving beliefs, challenges, and needs, with mothers in both groups becoming unequivocally consumed by the role that they undertake. However, the present findings suggest that those with a history of AN may face unique psychological and behavioural adversities, necessitating tailored support and interventions not only to bring them much needed relief, but also to enhance the care they are able to provide for their daughters.

4.3 Clinical implications for practice and Counselling Psychology

The findings from this study shed light on the challenges and opportunities involved in caring for a daughter with active AN as a mother who is recovered from AN, a topic so far poorly researched. It is hoped that they can be of use to both Counselling Psychologists and other MH professionals working in EDs. Their clinical implications are discussed below.

Firstly, the study has provided significant evidence for the importance of taking the needs of carers into consideration when presented with a young person with AN, particularly as the demands and mental and physical impact of the role are widely known, yet participants often feel they have no choice but to put their child's needs and health over their own. A routine initial carer assessment could be introduced to determine their psychological needs, and in particular, to establish whether there is any history of AN. A proactive measure such as this, would ensure that any psychological vulnerabilities are addressed early, in the hope of preventing, or at least mitigating, distress levels, and the resurgence of carers' own AN. Individually tailored psychological support could then be made available to them should they need it, with a focus on reduced waiting times, recognising the critical role they play in their child's recovery and, in the case of AN reoccurrence, regular psychological monitoring could be incorporated.

The present findings also support the provision of timely signposting to relevant resources and support groups, vital in ensuring mothers are supported and informed about AN and their role in the recovery process, particularly in the context of NHS resource constraints. Specific support programmes have been developed to meet the needs of carers in other areas of MH (e.g. Charlesworth, 2001), yet these remain lacking in EDs, something that urgently needs addressing. Psycho-education should however not be limited to PCs, as the study highlighted the need for more attention to be given to the role of fathers in the caregiving process, as well as to the needs of siblings and the family system as a whole, which may require both individualised and FBT. In line with previous calls from parents (Haigh & Treasure, 2003), targeted support around meals, such as in-home care services or caregiver training on specific strategies, could help to alleviate the stress and distress that were found to accompany family meals.

Although it is vital to improve carer support, the study showed that much of the distress experienced by carers would likely be significantly reduced if changes were made to healthcare quality, systems and process, with particular regard to CAMHS. Firstly, regarding access to care, the findings support calls for improved training around EDs for professionals in PC (some made by the professionals themselves), so they can offer better support to individuals and their families at this early stage, and to ensure they do not under or over refer to specialist services (Roots et al., 2009; Johns et al., 2019). Participants in the study also flagged, yet again, the pressing need for reduced waiting times within the NHS and the disparity in the availability and speed of care across geographical locations, which only those in a position of financial privilege can circumvent. A more equitable healthcare access could perhaps be achieved through a concerted effort to standardise access to care across regions, and increased funding in underserved areas.

The use of BMI as a referral and diagnostic tool also came under heavy criticism here as this outdated, counterproductive tool, perhaps ironically used to conserve resources for those 'ill enough', seemed to delay inevitable treatment until the AN worsened to the point at which more intensive, long-term, costly care was required. A more holistic approach to referral is therefore recommended, wherein the broader indicators of AN would be considered, including the valuable perspectives of mothers, to establish a more comprehensive understanding of the young person's presentation, permitting more accurate and timely referrals and the subsequent mitigation of AN progression.

A final implication concerns the standard of care received once through the many barriers, particularly in relation to CAMHS. Participants denounced the one-size fits all approach to AN often used, which fails to address the idiosyncratic nature of AN (Treasure et al., 2015) even though the implementation of flexible, tailored, individualised care is vital for effective treatment and outcomes. Furthermore, the transition from CAMHS to AMHS was seen as a disjointed and highly stressful process by caregivers, who feared the day their daughter would be "dropped" from care regardless of where in their recovery journey they sat. As discussed, continuity of care is essential in the reduction of relapse risk and ongoing recovery support (Singh et al., 2010), and this, and a smoother transition, could perhaps be achieved through improved communication and coordination between MDTs across the two services, and of course, through reduced waiting times, as these are considerably higher in adult MH care (Beat, 2017) [15].

Many of the clinical implications identified are applicable to wider caregiving contexts. The likelihood of these measures being implemented may be low due to a lack of resources, yet shifting to preventative care for EDs could ultimately free up resources within the nine billion pounds that treatment is currently costing the NHS annually (Hearts, Minds, Genes Coalition for EDs, 2020). Investment in early intervention strategies and comprehensive support for caregivers with or

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[15] Following an investigation into five preventable deaths, on 6th November, 2020, the coroner for Cambridgeshire and Peterborough declared that the NHS AN treatment is "not a safe system", and poses a risk of "future deaths" (Ayton, 2020). This echoes a 2017 report by the Parliamentary Health Service Ombudsman, who issued a number of constructive recommendations, including improving the healthcare workforce, reassessing medical training, improving care coordination, and ensuring equal funding across services for all age groups, three years prior. Despite this, progress has been limited since.

without a history of AN, could therefore constitute a cost-effective strategy for the NHS, while having positive ramifications for patient and carer outcomes.

4.4 Critical Evaluation of the study

4.4.1 Strengths

A strength of this study, as discussed in further detail in the methodology chapter, is the adherence to Yardley's (2000) suggested criteria for achieving quality and validity, as recommended by Smith (2022).

It has been argued by Yardley however, that the development of a thorough and sensitive analysis is insufficient, if the findings are of little impact. As discussed in the literature review, while the experience of caring for a child with AN has been extensively researched, that of recovered anorexic mothers caring for their anorexic daughters was an unexplored phenomenon. The present study therefore helped address a significant gap by offering novel phenomenological, in-depth insights, and also gave voice to participants so far largely ignored in qualitative research around AN.

4.4.2 Limitations

Despite the strengths of the study, it is not without its limitations. First, it is important to recognise that, while credible, the findings of this study are not the sole credible interpretation (Smith et al., 2009), and that different conclusions might have been drawn by a different researcher working at a different time and with a different group of participants. Furthermore, IPA requires that participants articulate the richness of their experience through language; not always an easy thing to do (Willig, 2013). Interestingly, there were instances throughout the interviews in which participants struggled to communicate their experiences and thoughts. In line with the study's phenomenological approach, and to the extent that communicating through videoconference allowed, I paid close attention to body language or changes in tone at all times. I also made notes of any non-verbal communication when analysing the data, such as laughter, pauses or hesitations.

The selection of the study's participants must also be considered here. The reason for recruiting mothers was explained earlier, and it resulted in a homogeneous sample befitting IPA. However, it meant that only limited and indirect insight could be generated into the experiences of other family members, including those of people who may also have acted as carers. Furthermore, the self-selected sample lacked diversity alongside a range of relevant dimensions, including ethnic or racial backgrounds (a dimension important to explore given the growing literature surrounding the underdiagnosis of black women with AN – Sonneville & Lipson, 2018), with all mothers being white British, and relationship status, seeing that all but one participant was in a marital relationship and that any strengths or struggles specific to mothers in other types of relationships or situation (e.g., unmarried mothers) may not be represented, potentially limiting the applicability of the study's conclusions. This limitation reflects the lack of participant diversity acknowledged in the literature review, and therefore further underscores the barriers faced when trying to engage with underrepresented communities within ED research. Tailored recruitment strategies such as partnering with community organisations, through community-based participatory research for example, offering culturally sensitive recruitment strategies, and increased flexibility of participation formats could be utilised to help overcome barriers, and facilitate broader participation. Addressing researcher diversity ought to also be considered here.

The participants' daughters were at different stages in their recovery, with some considered to be very much 'through the other side' whereas others, while meeting the criterion of being in stable recovery, with the worst part behind them, were still receiving significant levels of support. This could of course have significantly influenced participants' narratives, affecting perspectives, emotional responses, and depth of recall due to temporal distance. Related to this, all accounts could have been subject to recall bias, due to the retrospective nature of the storytelling (Hassan, 2005; Sutton et al., 2022). However what is of interest to an IPA researcher is participants' *perception* of reality, so this need not detract from the validity of the findings (Koriat et al., 2000; Alase, 2017).

A final limitation concerns the small sample size. For reasons already presented, only six women could be interviewed here. Still, the sample size remains within acceptable bounds as defined by Smith, Flowers and Larkin (2022) for a Professional Doctorate, while the rich data collected allowed for the generation of complex, transferable insights around the experience of interest.

4.5 Future research

Through conducting this research project, areas of research that perhaps warrant further exploration have been identified. Firstly, given the absence of research on recovered anorexic mothers caring for their anorexic daughters, there is ample scope for additional studies using larger and/or more diverse samples, which could address some of the methodological limitations described above.

Although ethical issues would need to be carefully considered, additional research could explore the experience of mothers looking after their anorexic daughters while simultaneously suffering from active AN.

Studying the daughters' side of the story, namely how they understand their mother's experience of AN, and how it may relate to their own, could also help tailor clinical interventions aimed at facilitating a collaborative relationship between them. Getting the perspective of other family members, including fathers and siblings, on how they understand the impact of AN on mothers and daughters with the illness would also be valuable, notably to clinicians working with family groups.

A gap in the literature was also identified that when addressed, should parallel the focus of this study, but this time looking at other psychopathologies such as OCD.

4.6 Conclusion

This study has offered an in-depth, phenomenological insight into the experience of recovered anorexic mothers, caring for their anorexic daughters, and to my knowledge, is the first to do so. The findings generated build upon existing literature as well as providing new insights into the specific experience of recovered anorexic mothers, and have a number of significant implications for healthcare policy and clinical practice. I am passionate about improving ED treatment, and I hope that once disseminated through publication, these findings will in some way influence the work of CPs and other health professionals working towards a safer system of care for those with anorexia nervosa.

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Appendices

Appendix 1

SCOFFF Questionnaire – Test for Detecting Eating Disorders

*** SCOFF Questionnaire ***

1. Do you make yourself **S**ick because you feel uncomfortably full?

   Yes
   No

2. Do you worry you have lost **C**ontrol over how much you eat?

   Yes
   No

3. Have you recently lost more than **O**ne stone in a 3 month period?

   Yes
   No

4. Do you believe yourself to be **F**at when others say you are too thin?

   Yes
   No

5. Would you say that **F**ood dominates your life?

   Yes
   No

Interpretation of Results

If you answer ‘No’ to every question, the test indicates you do not have an eating disorder.

If you answered Yes to at least 2 questions, the test indicates you may have **Anorexia Nervosa** or **Bulimia Nervosa.** This is not a diagnosis.

Adapted from: Morgan, J. F., Reid, F., & Lacey, J. H. (1999). The Scoff Questionnaire: Assessment of a new screening tool for eating disorders. *BMJ*, *319*(7223), 1467–1468.

Appendix 2

Department of *Psychology*
City, University of London

PARTICIPANTS NEEDED

ARE YOU THE MOTHER OF A DAUGHTER WITH ANOREXIA NERVOSA? HAVE YOU SUFFERED FROM ANOREXIA NERVOSA IN THE PAST? IF SO, I WOULD REALLY LIKE TO HEAR FROM YOU

I am looking for volunteers to take part in a study exploring what it is like for a recovered anorexic mother to care for their anorexic daughter, with the aim of bettering support for those in need of help.

Your participation would involve one interview lasting approximately *60 to 90* minutes. All the information collected will be made anonymous and kept confidential.

For more information or to volunteer for this study,
please contact Charlotte Bradley at [redacted]

The research is supervised by [redacted]

This study has been reviewed by, and received ethics clearance
through the Psychology Research Ethics Committee, City, University of London

If you would like to complain about any aspect of the study, please contact the Secretary to the Senate Research Ethics Committee on [redacted]

City, University of London is the data controller for the personal data collected for this research project. If you have any data protection concerns about this research project, please contact City's Information Compliance Team at [redacted]

Appendix 3

Screening Call Questionnaire

1. What is your age?
2. Did you receive a formal diagnosis of Anorexia Nervosa in the past? If yes, at what age?
3. Are you now in recovery? (Symptom free, and no longer in treatment)
4. Was your daughter formally diagnosed with Anorexia Nervosa? If so, at what age?
5. Did you care for your daughter when she was diagnosed with Anorexia Nervosa?
6. Did you enter recovery before your daughter’s diagnosis?
7. Is your daughter now in recovery? If so, for how long?
8. Do you have any questions?

Appendix 4

Participant Information

REC reference number, date and version of information sheet

ETH2223-0432

Title of study

The experience of recovered anorexic mothers, caring for their anorexic daughters: A qualitative study

Name of principal investigator/researcher

Charlotte Bradley

Invitation paragraph

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. You will be given a copy of this information sheet to keep.

What is the purpose of the study?

This study is the basis of a thesis within a professional doctorate in counselling psychology. My hope is that the study will help health professionals better understand the experience of recovered anorexic mothers caring for anorexic daughters, and thus provide better support. The study will take approximately two years to complete, including write up.

Why have I been invited to take part?

You have been invited because you have previously suffered from Anorexia Nervosa and you have experience caring for a daughter who has also had AN. There will be 5 other participants.

Do I have to take part?

No, participation is voluntary, and you can choose to participate in part or all of the project. Even if you do decide to take part, you are able to withdraw at any stage, and avoid answering questions you do not wish to answer. You can withdraw at any stage of the project without being penalised or disadvantaged in any way, and without giving a reason. If you do decide to take part, you will be asked to sign a consent form. Once the data has been anonymised or analysed, participants will no longer be able to withdraw their data.

What will happen if I take part?

The study will involve one interview lasting approximately 60 – 90 minutes, in which the researcher will ask you questions about your experience caring for your daughter with anorexia. If conducting face-to-face, the researcher will expect the participant to come to City University, or the researcher will go to your home, depending on your preference. If the interview is conducted online, you will be expected to use Zoom.

What are the possible disadvantages and risks of taking part?

The only disadvantage of taking part in this study would be discussing potentially upsetting experiences if you choose to disclose them. However, you will have the right to withdraw from the study at any given time if you feel uncomfortable, or do not wish for me to use your answers.

A possible benefit of taking part would be contributing to research that could improve future treatment for people with Anorexia Nervosa and those caring for them.

Data privacy statement

City, University of London is the sponsor and the data controller of this study based in the United Kingdom. This means that we are responsible for looking after your information and using it properly. The legal basis under which your data will be processed is City's public task.

Your right to access, change or move your information are limited, as we need to manage your information in a specific way in order for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personal-identifiable information possible (for further information please see https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/public-task/).

City will use your name and contact details to contact you about the research study as necessary. If you wish to receive the results of the study, your contact details will also be kept for this purpose. The only person at City who will have access to your identifiable information will be the researcher. City will keep identifiable information about you from this study for 1 years after the study has finished.

You can find out more about how City handles data by visiting https://www.city.ac.uk/about/governance/legal. If you are concerned about how we have processed your personal data, you can contact the Information Commissioner's Office (IOC) https://ico.org.uk/.

Will my taking part in the study be kept confidential?

All data will be anonymised for the write up, however beforehand, only the researcher and the research supervisor will have access to the information. Any identifiable information will be changed if transcribed.

All information will be kept confidential, unless there is any risk of harm to the participant of others, then the appropriate services would be contacted.
Data will be encrypted on the recording device and laptop.

What will happen to the results?

The results will be published within the thesis in 2024, and anonymity will be maintained. If you would like to receive a copy of the result, I will require you to explicitly consent to your data being kept for this purpose.

Who has reviewed the study?

This study has been approved by City, University of London *Psychology* Research Ethics Committee.

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through City's complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is The experience of recovered anorexic mothers, caring for their anorexic daughters: A qualitative study.

You can also write to the Secretary at:

[redacted]
Research Integrity Manager
City, University of London, Northampton Square
London, EC1V 0HB
Email: [redacted]

Insurance

City holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

Further information and contact details

Researcher: Charlotte Bradley: [redacted]
Supervisor: [redacted]

Thank you for taking the time to read this information sheet.

Appendix 5

CITY
UNIVERSITY OF LONDON
EST 1894

Consent Form

Principal researcher: Charlotte Bradley

REC reference number: ETH2223-0432

Title of study: The experience of a recovered anorexic mothers, caring for their anorexic daughters

		Please tick or initial box
1	I confirm that I have read and understood the participant information dated XXX for the above study. I have had the opportunity to consider the information and ask questions which have been answered satisfactorily.	
2.	I understand that my participation is voluntary and that I am free to withdraw without giving a reason without being penalised or disadvantaged.	
3.	I understand that I will be able to withdraw my data for up to six weeks after the interview	
4.	I agree to the interview being audio recorded.	
5.	I agree to the use of direct quotes from the interview in the write up, as long as all identifiable details have been removed.	
6.	I agree to provide demographic data by means of a short questionnaire	
7.	I agree to City recording and processing this information about me. I understand that this information will be used only for the purpose(s) explained in the participant information and my consent is conditional on City complying with its duties and obligations under the General Data Protection Regulation (GDPR).	
8.	I would like to be informed of the results of this study once it has been completed and understand that my contact details will be retained for this purpose.	
9.	I agree to take part in the above study.	

Name of Participant ______________________ Signature ______________________ Date ______________

[redacted]

Name of Researcher Signature Date ______________

When completed, 1 copy for participant; 1 copy for researcher file.

Appendix 6

Interview schedule

1. Please could you share a little about your experience with, and recovery from Anorexia Nervosa?

2. Can you tell me about your daughter's difficulties?
   Prompt: Can you tell me how this started? Difficulties around food/weight/body image? Other difficulties?

3. What was it like for you to care for your daughter after she developed anorexia? Did you experience any changes in your day-to-day life? Can you give examples?
   Prompts: Difficulties/Changes around mealtimes? Changes/difficulties around going out/having to dress up? Changes in your relationship with your daughter? With other family members? Other people? Could you take me through a typical day?

4. Can you describe how your child's illness affected you personally?
   Prompts: Impact on thinking and emotions? Impact on health? Impact on social life? Experience of food, weight concerns, or body image? Impact on how you saw/see yourself?

5. What helped you cope with/manage the situation? What made it harder to cope?

6. As a parent, what did you feel you needed to help best support your daughter?

7. What was your experience like with health professionals?

8. Do you feel that having had anorexia nervosa yourself, affected how you cared for your daughter? How so? Can you share examples?

9. Before we end the interview, is there anything you would like to add that might help me better understand your experience of caring for your daughter?

Appendix 7

Demographic Questionnaire

9. What is your ethnicity?
10. Where in the UK do you live?
11. What is your employment status?
12. What is your highest level of education?
13. What is your relationship status?
14. How many children do you have? If multiple, number and age?

Appendix 8

The experience of recovered anorexic mothers caring for their anorexic daughters: A qualitative study

DEBRIEF INFORMATION

Thank you for taking part in this study. Now that it's finished we'd like to tell you a bit more about it.

This study is aiming to explore and develop a greater understanding of a mother's experience, as a recovered anorexic, caring for her anorexic daughter. The specific questions asked were to cover areas of interest, whilst also allowing you to guide the conversation, and sharing what you felt comfortable.

I hope the research provides in depth insight into the experience of mothers caring for a daughter with anorexic nervosa, after having had the illness themselves, so that we as mental health professionals, can better understand how and what support would make that experience more manageable.

If you found any part of the interview upsetting or distressing, I encourage you to either contact your GP, or utilise and of the contacts and websites below:

Beat
The UK's Eating Disorder Charity, supporting and educating those with an ED or those caring for them.
0808 801 0677
https://www.beateatingdisorders.org.uk/\

Mind
Charity providing advice and support for anyone struggling with a mental health problem
0300 123 3393
https://www.mind.org.uk/

Anorexia & Bulimia Care
UK organisation with over 30 years experience, providing care, support, and guidance for those affected by eating disorders and distress.
03000 111 213
https://www.anorexiabulimiacare.org.uk/

We hope you found the study interesting. If you have any other questions, please do not hesitate to contact us at the following:

Charlotte Bradley: Email: [redacted]

[redacted]

Ethics approval code:

Appendix 9

Ethical approval

Dear Charlotte

Reference: ETH2223-0346

Project title: The experience of recovered anorexic mothers, caring for their anorexic daughters: A Qualitative Study

Start date: 24 May 2022

End date: 30 Sep 2023

I am writing to you to confirm that the research proposal detailed above has been granted formal approval from the Psychology committee: medium risk. The Committee's response is based on the protocol described in the application form and supporting documentation. Approval has been given for the submitted application only and the research must be conducted accordingly. You are now free to start recruitment.

Please ensure that you are familiar with City's Framework for Good Practice in Research and any appropriate Departmental/School guidelines, as well as applicable external relevant policies.

Please note the following:

Project amendments/extension

You will need to submit an amendment or request an extension if you wish to make any of the following changes to your research project:

- Change or add a new category of participants;
- Change or add researchers involved in the project, including PI and supervisor;
- Change to the sponsorship/collaboration;
- Add a new or change a territory for international projects;
- Change the procedures undertaken by participants, including any change relating to the safety or physical or mental integrity of research participants, or to the risk/benefit assessment for the project or collecting additional types of data from research
- participants; Change the design and/or methodology of the study, including changing or adding a new research method and/or research instrument;
- Change project documentation such as protocol, participant information sheets, consent forms, questionnaires, letters of invitation, information sheets for relatives or
- carers; Change to the insurance or indemnity arrangements for the project;
- Change the end date of the project.

Adverse events or untoward incidents

You will need to submit an Adverse Events or Untoward Incidents report in the event of any of the following:

a) Adverse events

b) Breaches of confidentiality

c) Safeguarding issues relating to children or vulnerable adults

d) Incidents that affect the personal safety of a participant or researcher

Issues a) and b) should be reported as soon as possible and no later than five days after the event. Issues c) and d) should be reported immediately. Where appropriate, the researcher should also report adverse events to other relevant institutions, such as the police or social services.

Should you have any further queries relating to this matter, please do not hesitate to contact me. On behalf of the Psychology committee: medium risk, I do hope that the project meets with success.

Kind regards

[redacted]

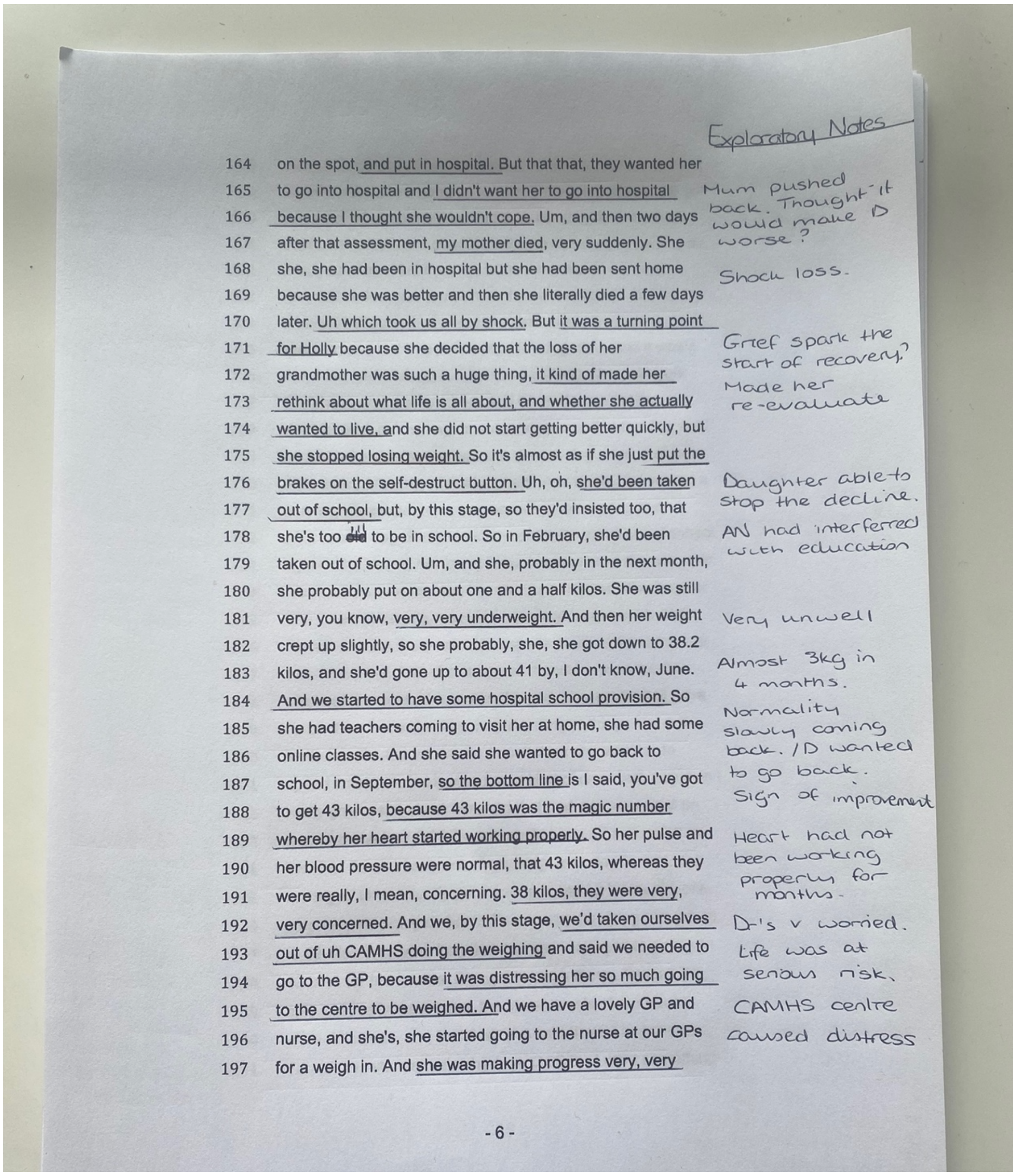
Psychology committee: medium risk

City, University of London

Appendix 10

Sample of analysis: Exploratory Noting and Experiential Statements

a.



Exploratory Notes

on the spot, and put in hospital. But that that, they wanted her to go into hospital and I didn't want her to go into hospital because I thought she wouldn't cope. Um, and then two days after that assessment, my mother died, very suddenly. She she, she had been in hospital but she had been sent home because she was better and then she literally died a few days later. Uh which took us all by shock. But it was a turning point for Holly because she decided that the loss of her grandmother was such a huge thing, it kind of made her rethink about what life is all about, and whether she actually wanted to live, and she did not start getting better quickly, but she stopped losing weight. So it's almost as if she just put the brakes on the self-destruct button. Uh, oh, she'd been taken out of school, but, by this stage, so they'd insisted too, that she's too ~~old~~ ill to be in school. So in February, she'd been taken out of school. Um, and she, probably in the next month, she probably put on about one and a half kilos. She was still very, you know, very, very underweight. And then her weight crept up slightly, so she probably, she, she got down to 38.2 kilos, and she'd gone up to about 41 by, I don't know, June. And we started to have some hospital school provision. So she had teachers coming to visit her at home, she had some online classes. And she said she wanted to go back to school, in September, so the bottom line is I said, you've got to get 43 kilos, because 43 kilos was the magic number whereby her heart started working properly. So her pulse and her blood pressure were normal, that 43 kilos, whereas they were really, I mean, concerning. 38 kilos, they were very, very concerned. And we, by this stage, we'd taken ourselves out of uh CAMHS doing the weighing and said we needed to go to the GP, because it was distressing her so much going to the centre to be weighed. And we have a lovely GP and nurse, and she's, she started going to the nurse at our GPs for a weigh in. And she was making progress very, very

Mum pushed back. Thought it would make D worse?

Shock loss.

Grief spark the start of recovery?

Made her re-evaluate

Daughter able to stop the decline.

AN had interferred with education

Very unwell

Almost 3kg in 4 months.

Normality slowly coming back. / D wanted to go back.

Sign of improvement

Heart had not been working properly for months.

Dr's v worried.

Life was at serious risk.

CAMHS centre caused distress

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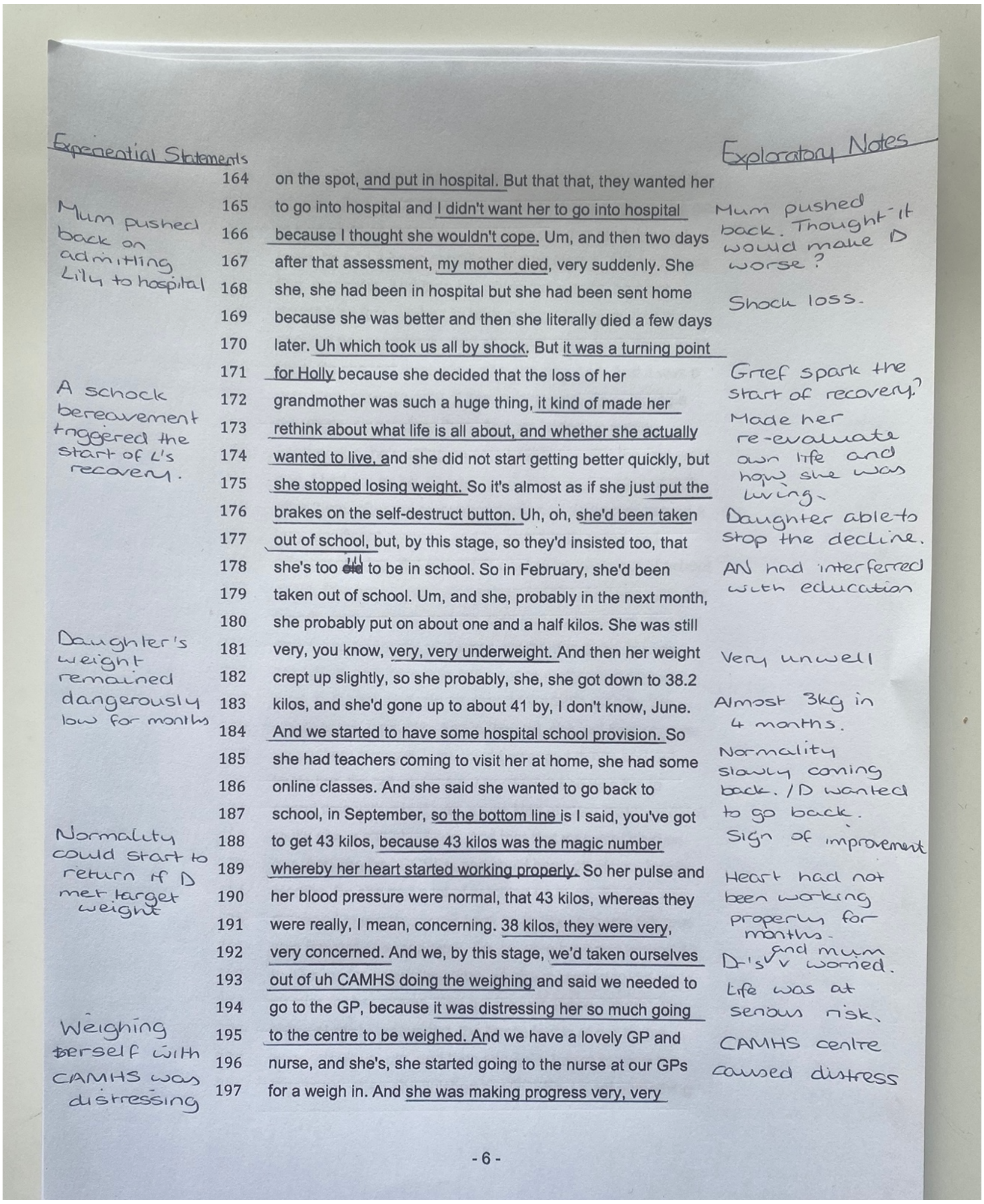
Sample of analysis: Exploratory Noting and Experiential Statements cont.

b.



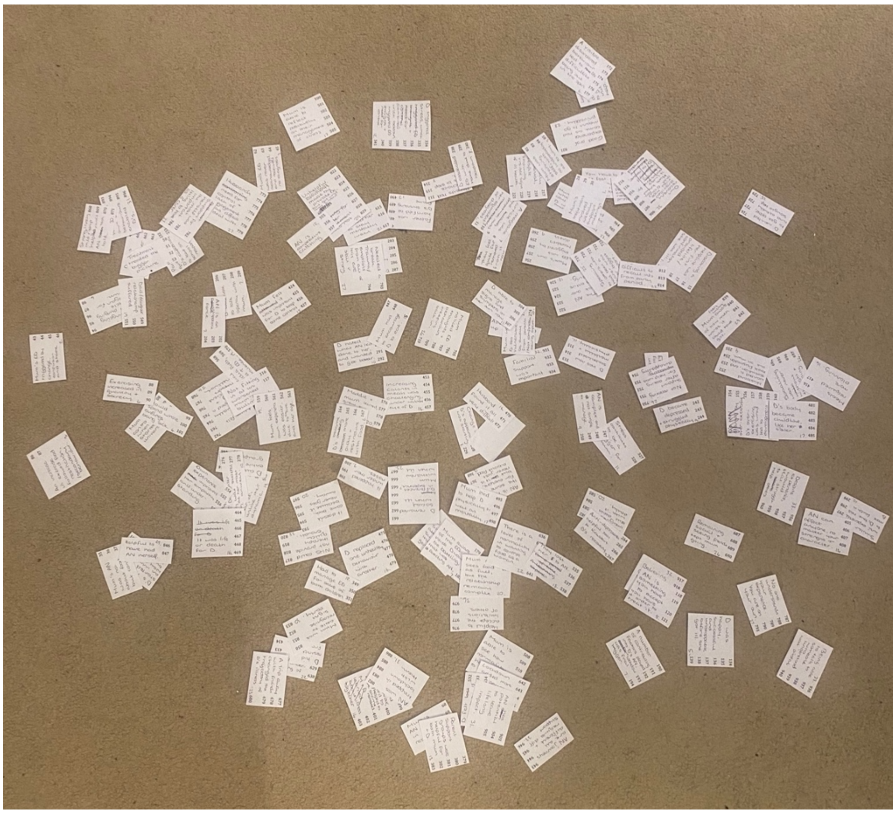
Experiential Statements		Exploratory Notes
Mum pushed back on admitting Lily to hospital	on the spot, and put in hospital. But that that, they wanted her to go into hospital and I didn't want her to go into hospital because I thought she wouldn't cope. Um, and then two days after that assessment, my mother died, very suddenly. She she, she had been in hospital but she had been sent home because she was better and then she literally died a few days later. Uh which took us all by shock.	Mum pushed back. Thought it would make D worse? Shock loss.
A schock bereavement triggered the start of L's recovery.	But it was a turning point for Holly because she decided that the loss of her grandmother was such a huge thing, it kind of made her rethink about what life is all about, and whether she actually wanted to live, and she did not start getting better quickly, but she stopped losing weight. So it's almost as if she just put the brakes on the self-destruct button.	Grief spark the start of recovery? Made her re-evaluate own life and how she was living. Daughter able to stop the decline.
	Uh, oh, she'd been taken out of school, but, by this stage, so they'd insisted too, that she's too ~~old~~ ill to be in school. So in February, she'd been taken out of school.	AN had interferred with education
Daughter's weight remained dangerously low for months	Um, and she, probably in the next month, she probably put on about one and a half kilos. She was still very, you know, very, very underweight. And then her weight crept up slightly, so she probably, she, she got down to 38.2 kilos, and she'd gone up to about 41 by, I don't know, June.	Very unwell Almost 3kg in 4 months.
Normality could start to return if D met target weight	And we started to have some hospital school provision. So she had teachers coming to visit her at home, she had some online classes. And she said she wanted to go back to school, in September, so the bottom line is I said, you've got to get 43 kilos, because 43 kilos was the magic number whereby her heart started working properly. So her pulse and her blood pressure were normal, that 43 kilos, whereas they were really, I mean, concerning. 38 kilos, they were very, very concerned.	Normality slowly coming back. / D wanted to go back. Sign of improvement Heart had not been working properly for months. Dr's and mum v worried. Life was at serious risk.
Weighing herself with CAMHS was distressing	And we, by this stage, we'd taken ourselves out of uh CAMHS doing the weighing and said we needed to go to the GP, because it was distressing her so much going to the centre to be weighed. And we have a lovely GP and nurse, and she's, she started going to the nurse at our GPs for a weigh in. And she was making progress very, very	CAMHS centre caused distress

- 6 -

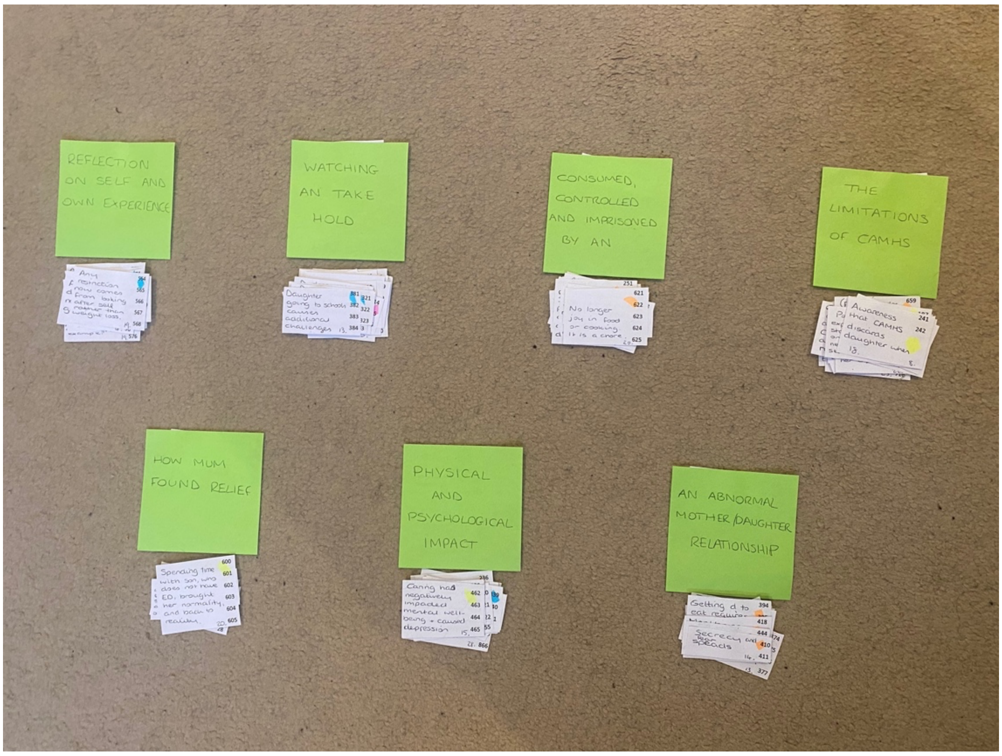
Appendix 11

Sample of analysis: The process of grouping Experiential Statements

a.



b.



Appendix 12

Sample of analysis: PETs Table

HEALTHCARE - A BROKEN SYSTEM	**IMPACT ON RELATIONSHIP AND HOMELIFE DYNAMIC**	**A TRAUMATIC EXPERIENCE**
The help available "lets eating disorders down"	**Mother and daughter faced challenes, but were lucky to have a good relationship**	**Was this my fault?**
After initial weight gain, Janet received no ongoing support to increas weight, becoming stuck (p.3) *"I stayed the same weight, and that scale probably didn't move for about a year. It did not move. But I din't get any help with it."*	Hannah would lie to her mum (p. 11) *"It's the lying.. So when she tells me things now, I don't actually know whether she's telling me the truth or not. Most of the time she actualy is. I don't know whether sometimes I don't know whether to believe her or not. She lied so much when she had the anorexia, but sometimes she would tell me something and it is actually the truth and she said 'mum, i'm telling you the truth but you don't know whether to believe her or not, because of the lies and deceit that came with the anorexia."*	Was this my fault? Mum thought she had hidden it (p.15) *"Where did she get this from? You know, have I given it to her? Because Hannah didn't know I had an eating disorder. I never told her."*
Despite severity, mum had to initiate more serious care (p.) *"I was emailing them with her weight, and they weren't really taking it very seriously. So it got to the point that I spoke to them and I said I think she needs to go into hospital."* *"So they did actually, they were humming and harring abou tit, so I actually myself rang up The Priory, and they said just get the urse to send the details over, and she was in within the week after."*	The conflict did not ruin their relationship (p.11) *"We still stayed close, um, but we would argue, so she would say things to me, I'd say things to her that afterwards..would be regretting it."*	Sometimes, both mum and daughter put the blame on mum (p.15) *"She had no idea I'd had an eating disorder. So I never told her. So you just think, and I know they talk about it being genetic and things like that, but I just think.. You think to yourself, a lot of the time she says to me, it's your fault. You shouldn't have had me, because you had me, I've got this. Well I do blame myself sometime that, she has this becasuese of me , because I had it. But yea, it's, it's awful, really.*
Mum received minimal professional support through 13 year battle with anorexia (p.1) *"I had anorexia for 13 years, um, and I didn't have very much help when I was ill, you were literally sent to a mental health team. There wasn't like the services there are now to help you."*	Health professionals saw their close relationship as helpul for recovery (p. 26) *"I remember the professionals saying to me, you two have got a great relationship, and it's very good how, you sit down together and talk about it. But he said to me, a lot of families aren't like this, that's why they have to have family therapy. We didn't have family therapy, because they didn't feel we needed it at the time, because we were communicating together."* *"They'd say, you know, you've got a good bond, and she's very honest, because even when we had consultations, or she wanted me in the room, they used to say 'are you sure you want your mum in the room?' and she said yeah, that's my best friend. She knows everything. So, they actually were quite happy with the fact that she was so open, so honest about* the illness before she went into hospital, and was able to say in front of me as well."	Mum didn't notice the early signs (p. 5) *"I didn't really take any, any notice of it, that she was cutting carbs out. I wasn't really aware that she was missing meals, because she was at, you know, sixth form all day."*
NHS funding is not being used effectively or efficiently (p.22) *"They don't have that specialised treatment, and I think it would save the NHS so much money, with people coming into hospital like five, six, seven months. I mean that must cost a fortune."*	They began working together (p.20) *"We would sit down, have check-ins, we would talk about what they (Beat)suggesed and we'd try those methods. And that was really helpful."*	**Confronted with own (mother's) experience**
The NHS lets eating disorders down (p.22) *"The NHS has let, let down eating disorders to be hoenst. And when I speak to other carers, a lot of them have had to go private, because they can't get the help. "*	**Home life became controlled and restricted**	It was sad to realise the truth of her own AN past (p. 16) *"I used to get a lot of flashbacks, you think I must have looked at ill as how she looked. And that upset me to think that I became so ill."* "When I saw her so thin. It made me think my goodness, I must have looked really bad when I was ill."

Appendix 13

Sample of analysis: GETs Table

Mother's own experience was helpful	**With a greater understanding, came fear, collusion and false hope**	**Own anorexia was triggered, and came "creeping back in"**
Mum's own experiences improved her empathy and understanding *"I think I was probably a bit more empathetic and a bit more understanding of it having been through it, I think it really.. Having been through an eating disorder myself, I think, I think it really helped. We picked it up early. The.. I understood, those feelings."* (Helen, p. 19)	Mum worries that her own disordered behaviours enabled her daughter's *"Yes, a little bit because if I behaved in an eating disorder way in front of Maddie, it would give her justification to do the same. Um, so, I suppose when, when my eating disorder habits, established or, or sort of came back, it was a sort of confirmation for Maddie, that she was doing the right thing, it was sort of made it harder for her to fight, or to go agianst her gut instinct then, which was to restrict her food. Does that make sense?"* (Helen, p. 31)	Mum noticed disordered thoughts and behaviours creeping back in *"It definitely triggered lots of those feelings about it. I, I expect I started behaving a little bit like.. Um, so disorder, eating disorder habits, sort of, I would definitely try and skip a meal. If Maddie wasn't noticing. Um, I would definitely.. had in my mind that I had to be slim. um, yea, so I, I definitely was triggered. Yeah. Yeah, and that manifested into sort of, eating disorder behaviour. Definitely."* (Helen, p. 24)
Mum's own recovery provided vital hope that her daughter could too *"One key thing that I knew she could get better, and that's what kept us going. I kept on saying to her, you know, it, it will, you will be, yeah, the fundamental belief yeah, that's probably quite key, the fundamental belief, that um, I knew she would get better. I just said, just trust me, you will, you will get better, you will live a normal life like I have. I've had children, I have, I think a fairly good relationship with you." (Helen, p. 31)* *"A fundamental belief that, some parents might think that this is never going to change, this is never going to get better. And to have faith that it will, is quite empowering. And that you can, you know, you can A; get over the eating disorder, and B; live a normal life was yeah, was pretty fundamental. And I truly believed, um, and I was able to say this to her, you know, you will be ok. You will get better. It's just a question of time." (Helen, p.* 32)	Feels own experience meant she got too involved *"If I had no experience of it..... maybe I would have just insisted that we all sat down to eat, and that, um, you know, that I didn't try and manage everything in the way I did, sort of controlling everything, it would have just been.. ah I mean I think that's partly my character anyway, but things might have been different."* (Sarah, p. 31)	Mum's own eating disorder was triggered by Maddie's illness *"It was definitely triggered by Maddie's problems. And um, I remember talking to my doctor, and saying I'm really struggling again."* (Helen, p. 9)
Mum was able to recognise the signs early *"I could see it happening, I picked up on it very quickly, because I could, I recognised the behaviour."* (Helen, p. 30)	Tried to save her daughter. Help was a hinderance. *"My husband sometimes said that to me and said, you know, you're, you're kind of propping her up. And, and if you, you know, he didn't really, he didn't really know what, he didn't really say that, but it was on my thoughts that actually, maybe, by me saving her, it meant that she was not getting the help that she needed."* (Sarah, p. 32)	Mum had to managed her anorexia for the sake of both her children *"I'd have to set an example by not skipping meals you know, although Maddie was very, you know, 'Mummy have you had lunch today?' Um she'd pick up on it quite quickly. So I did have to sort of monitor my behaviour, and be aware of not triggering her."* (Helen, p. 12)
Own experience improved mothers understanding *"I knew what she was going through. I knew what those thoughts were. I knew that when she looked in the mirror and said that she was fat, I, I remember how awful that is because you actually do see a fat person in the mirror. You don't see a skinny person. So, I could understand what she was going through." (Janet, p. 23)* *"It was definitley easier, because I knew what she was thinking, and I could understand. I think sometimes, a person that hasn't had it, wouldn't understand someone saying, well I looked fat in this, when you know, they're so tiny, but I could relate to that, because you feel fat, you feel big, you feel uncomfortable." (Janet,* p, 25)	Collusion with daughter *"There was probably too much collusion on my part. And I use that word advisedly, because people have said that, they said to me that, and that I've been, I've colluded in her behaviour, and I think if I had I mean, I don't know, if I had had no experience of it. . . But I think I would have had to have a different relationship with her as well."* (Sarah, p. 31)	ED resurfaced under the guise of 'helping her to remember' *"You do sometimes have days when you don't eat, or overeat, because you're, it's like, I've had to do it to remind myself what it feels like. I sometimes forget how difficult it is living with an eating disorder. So some days, I've actually behaved as if I've got it, to try and remember how awful it is, for me to have a little bit of an understanding of how hard her day must be. Not very normal, but again, that's those behavours coming back. Like I said earlier, they never go away, they never go away."* (Janet, p. 16)

PART B

Combined Client Study and Process Report

[redacted]

This content has been removed for confidentiality purposes.

PART C: PUBLISHABLE PIECE

[redacted]

[redacted]