THE EXPERIENCES OF WOMEN WHO HAVE A CHILD DIAGNOSED WITH AN EATING DISORDER: A NARRATIVE INQUIRY

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THE EXPERIENCES OF WOMEN WHO HAVE A CHILD DIAGNOSED WITH AN EATING DISORDER: A NARRATIVE INQUIRY

by

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DISSERTATION

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Abstract

Eating disorders (EDs) are serious, life-threatening illnesses that typically occur in adolescence. Immediate intervention is necessary in order to interrupt the associated behaviours. Typically, adolescents struggling with EDs minimize the severity the illness has on their psychological and physiological wellbeing. For this reason, family involvement in the intervention is strongly recommended. Additionally, family involvement has shown to increase the likelihood of better outcomes. Parents are typically tasked with the responsibility of making and monitoring meals and/or interrupting compensatory behaviours. These tasks often lead to high conflict. Despite the importance of parental involvement, predominantly, it is mothers who fulfill the intensive and demanding caregiving role for their child. It is typically women who make numerous personal sacrifices to interrupt the ED. Current literature has not given attention to the reality that women are in intensive caregiving roles for their adolescent diagnosed with an ED, often for a prolonged period of time. Given their importance in treatment, it is vital to understand the experiences of women who have a child diagnosed with an ED. Using narrative inquiry, I interviewed ten women (seven married, three single) to learn of their experiences of caring for a child with an ED. Eight women were interviewed three times, two women were interviewed twice. Each interview ranged from 45 minutes to 160 minutes. The research question guiding this inquiry was: “What are the experiences of women who have a child diagnosed with an ED?” Four key storylines emerged. First, women were overwhelmed with the challenges of living daily with an ED. Second, they felt that numerous impossible expectations were placed upon them. Third, they felt that there was more to them than being mothers to their children. Fourth, though they were grateful that services existed, they needed more support. This study urges focusing research attention on adjusting and broadening current treatment models and gives a voice to women who are typically in the front lines of ED caregiving, yet whose stories remain untold.
Acknowledgements

While the journey through a PhD is a privilege and rewarding, it can also be a lonely and challenging endeavour. I am grateful to the many individuals who accompanied me on this journey to make it a less lonely experience, and provided wisdom, encouragement, strength, guidance, and humor at the times I needed it most.

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Chapter One: Introduction

“(Crying). Like I told you, it’s as if you are alone. You alone need to pull your daughter from the abyss into which she has fallen. She has fallen, and it’s all on you. You see the needle on the scale speeding down without stopping. You feel that you are going to lose her, as if she’s disappearing.” (Tuval-Mashiach et al., 2013, p.622)

Eating disorders (EDs) are serious and life-threatening illnesses that typically are diagnosed in adolescence (Smink et al., 2012). EDs have the highest mortality rate of any mental illness, making immediate intervention and arrest of symptoms crucial. A main feature of EDs is the sufferer’s lack of awareness of or insight into its severity. For this reason, and given that onset is typically in adolescence, parents are often tasked with restoring their child to health. However, it is mothers who primarily assume the challenging roles associated with caring for a child with an ED.

This dissertation focuses on the experiences of mothers who have a child diagnosed with an ED. Specifically, this research looks at the narratives of mothers and their experiences, struggles, successes, and understandings as mothers to children struggling with an ED.

The core rationale for this inquiry is to see these women as individuals with complex lives, to encounter them as people, not as a means to an end in treatment. This perspective is particularly important because “mothers appear to be the most beleaguered group in recent history” (Vander Ven & Vander Ven, 2003, p. 98), and this observation is particularly true when looking at the history of children with EDs where mothers were blamed for ED onset (Vander Ven & Vander Ven, 2003). Additionally, mothers are typically most present and active when their child is diagnosed with an ED, and they are the most representative sample in research involving parents or caregivers (Hughes et al., 2017). Despite being historically blamed and the
present need for their attendance in treatment, we do not know these women’s stories. Until we do, we continue to privilege the assumptions and expectations of what it means to be a mother to a child with an ED, instead of learning the reality of her life. One such assumption is that mothers would and should sacrifice everything in their lives and function solely for their children has guided treatment models. This point of view is problematic. I believe there is a danger when we assume what mothers should be tasked with when a child is ill with an ED. The rationale of this research is to humanize these women because they deserve to be seen beyond a means to an end in treatment.

The overarching question guiding this dissertation is: what are the experiences and expectations of women who have a child diagnosed with an ED? The main research questions that guide this overarching inquiry are: 1) What is it like to be a mother to a child with an ED? 2) What does her daily life involve? 3) How do mothers adapt to having a child with an ED? 4) How do mothers feel they are viewed by others (service providers, family members, general population)? 5) What do mothers feel they need to improve their lives while having a child with an ED? and 6) What implications do understanding these stories have for mothers’ well-being?

The objectives of this inquiry are to humanize these women and to gain a detailed understanding of their lives in the ED context. This inquiry did not use a single conceptual or theoretical framework; instead, I used the participants’ descriptions, existing evidence, and theory, and my own professional exposures, as lenses to guide my understanding and interpretation (Alvesson & Sköldberg, 2009).

It is important to note that this research does not address larger systemic issues, nor is this a psychological analysis of women and mothers. Additionally, this study does not attempt to situate women within a critical social perspective. Rather, I focus on an emergent approach that
allows women to speak from their own lived experience so the reader may learn how women understand and describe their realities.

**Social Location and Personal Motivation**

“Reflexive procedures, in which researchers engaged in a critical and conscientious evaluation of themselves in relation to the individuals or groups being researched, can substantially enhance the accuracy and ethical quality of social research by bringing awareness to influential aspects of one’s own biography and positioning that might otherwise remain hidden” (Goldstein, 2017, p. 149).

While the 10 years I spent working in the field of EDs was the catalyst that led me to pursue my PhD research, the focus on mothers arose from my personal experience combined with my professional experience. It is important to highlight my social location because my position of privilege has allowed me specific resources and opportunities in life, such as access to mental health services, that have helped me function at work and in academia. Additionally, my social location highlights my need to be cognizant of my own ignorance and bias. I am a married, Caucasian, heterosexual, child-free and able-bodied female with no religious affiliation. I grew up with two working parents and a brother. My mother is university educated. My father completed some college courses. Both were employed my whole life. I grew up in a middle-class family, in a predominately Caucasian town, outside of the Greater Toronto Area.

Several of my friends growing up struggled with weight issues and engaged in disordered eating behaviours. I never struggled with weight issues as a child, nor did I purposefully control my own weight, although I have always been cognizant of my appearance and body. This awareness is likely due to the image-focused environment in which I grew up and, because I am female, messages regarding body image and body expectations are targeted at me. Later in life,
my mother told me that she thought I was developing an ED as a teen because I had lost substantial weight and she did not witness me eating much. This was likely related to the mental health issues I struggled with: I was diagnosed with Major Depressive Disorder several years after the death of my brother.

For the five years of my life while my brother was sick, I witnessed my mother attempting to create a balance and establish normalcy, but also remain present and function. He was in and out of the hospital, awaiting a heart transplant, receiving a heart transplant, and then undergoing cancer treatment. My mother and father arranged with their employers to have at least one of them present at the hospital on a regular basis and also to be available for any emergencies that might arise. My mother arranged childcare for me during this time. My mother and father managed their schedules to be present for important events in my own life. The five years my parents spent in constant uncertainty and unrelenting exhaustion has motivated me to focus on the power that parents, specifically mothers, have to help their sick children and the challenges they encounter in doing so.

My mother and father had privileges that created an environment for them to be seen as successful in balancing their various roles and demands. Both of them had stable, permanent jobs with benefits. My mother and father were educated, spoke English, and were aware of the health care system; what they were not aware of, they were able to research and discover. Given that I grew up in a middle-class, suburban environment that was relatively close knit, my mother had support networks that were willing to assist her as needed during my brother’s illness; however, this shift in support changed when my mental health challenges surfaced.

While my mother did all she could to create a balance, it was impossible for her to dedicate equal time to my brother’s illness, her job, and my own needs. Growing up, I often felt
cast aside, an afterthought, and an added burden that they needed to arrange childcare for on top of all of their other ongoing stress. It was impossible for my mother and father to balance both a terminally ill child’s needs with their other child’s needs. When my brother died, attention shifted to me. In high school, I struggled with my mental health. I isolated myself, slept all day, and lost weight. In contrast to my brother’s illness, my mental health struggles remained a private, family matter given the stigma associated with mental illness. I witnessed my mother and father try to find ways to support me while also grieving the loss of their son. Again, my mother and father put their child’s needs ahead of their own. Yet this time, they did so without the support they had received earlier.

During my brother’s illness, I recall my mother, specifically, writing down in her notebook all information concerning my brother’s medical condition, as well as things to research when she got home from the hospital. She essentially became part of the medical team at the hospital. She was very involved in the hospital environment. She wrote an article for the hospital magazine, organized a transplant party at our home for the few children at the time who had undergone transplants, and represented the hospital at a fundraising telethon. Upon my brothers passing, she became an advocate for organ donation. She was an active member at Bereaved Families of Ontario.

When I was not well, I recall her in a different light. She was still supportive, but more of a private advocate for my well-being. She was the one who would break open the bathroom door when I had locked it. She was the one who attempted to connect with me through letters delivered to my room that conveyed her concern when I refused to speak. She advocated for me when my grades plummeted in high school, and she brought me to a psychiatrist when I was in crisis during my undergrad years at university. All the while, I had no idea what was going on
with her, and the experience and pressures that she felt. In fact, to this day, I still do not know. She has only told me snippets, and her eyes well up with tears as she does so.

My personal experience is intertwined with and influences my professional experience. I have been working in the field of EDs for over a decade and have seen many shifts in how the ED field interacts with caregivers over that short time. Completing a PhD has afforded me the privilege to pause and reflect on the interactions I have had with mothers over the course of my career. Regardless of whether I was working in an adult or a pediatric ED clinic, mothers were present in some capacity as either a support, an advocate, or an active member of the treatment team. The catalyst that led me to pursue a PhD focused on mothers was noticing my own burnout as a clinician. Working in this field is challenging (with factors discussed in the following chapter), and I noticed my hopeless feelings when I had no other tools to support families.

At the pinnacle of my burnout, I noticed my own frustrations toward parents, specifically mothers, when they were unable to carry out the treatment requirements. I reflected on conversations that I’d had with those in the ED field over the course of a decade and how we spoke about mothers: “treatment resistant,” “treatment interfering behaviours,” “poor coping,” “critical and hostile,” and “unproductive expressed emotions.” I admit that I assumed I understood these women’s realities. Upon reflection, this is not intended to be criticism of my peers, nor do I intend to criticize myself as a form of penance. Clinicians and mothers are both interacting with a complex illness along with challenging limitations within the healthcare system.

As clinicians, there are many things beyond the limits of our understanding. Most challenges cannot be solved by an individual service provider or team. Clinicians and mothers are up against the reality of the limits of our knowledge. The purpose of this dissertation, and
what ultimately brought me to complete it, is to learn from those in the frontlines of the work (in this case, mothers). I believe that parents, particularly mothers, are immensely powerful and necessary in assisting the recovery of their child. However, I also believe there has been a failure to see mothers as whole individuals with multiple roles and expectations.

**Additional Notes**

It is vital to note that the use of language pertaining to mothers and fathers is intentional. Throughout this study I try to avoid using the words *parents* or *caregivers*. Neutral terms such as these are misleading because they assume that mothers and fathers have similar experiences and expectations, thereby negating the unique experiences of these gendered roles.

Additionally, this study examines these roles through a hetero-normative, nuclear family lens. Single fathers, same sex couples, and other families of different constellations do exist in the ED world, but for the purposes of this investigation, these are beyond the scope of this research. Thus, this study is not intended to undermine or negate the fathers who are the prime caretakers for their ED child, nor non-traditional families that face unique additional challenges when they have a child with an ED. All face additional sets of challenges that would benefit from future research.

Finally, I want to reiterate that this dissertation does not question the professional competence of those working within this system. Those working in the ED field are engaging with a complicated service and support environment and a challenging illness. There is much that is beyond our immediate capacity to understand and to influence. The purpose of this dissertation is to point us to things we need to learn in order to create a more supportive system for those who are on the frontlines: specifically, mothers and by implication clinicians and other service providers.
Again, the focus of this dissertation is on understanding these mothers’ lives to improve our individual and collective helping, rather than prescribing how to do so. Practical considerations and assessments of how to reform what we do are where our attention needs to turn to build upon this work.
Chapter Two: Context

Nature, Prevalence, and Consequences of EDs

ED is an overarching term used to describe an array of diagnoses (e.g., anorexia nervosa, bulimia nervosa, binge eating disorder). EDs are serious, life-threatening disorders that affect every system of the body. EDs generally are diagnosed between the ages of 13 and 19 (Fisher et al., 1995; Smink et al., 2012; Weaver & Liebman, 2011), although there is emerging evidence that the onset of EDs is earlier (Favaro & Santonastaso, 2016).

Achieving accurate numbers for the prevalence of EDs is difficult owing to the secrecy associated with the illness and the reluctance to seek support. In addition, treatment drop-out rates are high (Smink et al., 2012). Regardless, while the number of new cases diagnosed has remained stable since the 1970s, there have been cases of the illness appearing earlier in life (Fisher et al., 1995; Madden et al., 2009; Smink et al., 2012; Weaver & Liebman, 2011). Specifically, there has been a 42% increase in diagnosed EDs for 10- to 19-year-old females and increases in hospitalizations for that same age range (Canadian Institute for Health Information, 2014). It is unknown if the rate in hospitalization is a result of increases of severe ED cases needing intensive treatment, a higher rate of EDs in general, or better identification of EDs (Rikani et al., 2013; Smink et al., 2012).

The number of individuals suffering from an ED at any given point in time is higher because of the lengthy duration of EDs. A full recovery takes on average from two to five years (Birmingham, 2004, p. 167; Herzog et al., 1997).

EDs are generally thought of as Caucasian, female, upper-middle-class afflictions, but the demographics of EDs are changing. In clinical samples, 5–10% of individuals are male (Hoek, 2002). Because EDs are considered to be a female disease, there could be an underreporting of
males who are suffering from EDs in the community. Collier (2013) states that historically it was thought that 10% of men had EDs such as anorexia nervosa (AN) or bulimia nervosa (BN), but current literature suggests that it may be closer to 25%. When binge-eating disorder is factored in, the statistics show that 40% of those in ED treatment samples are male (Collier, 2013; Rikani et al., 2013). Generally, males with EDs are “misunderstood, underdiagnosed and undertreated” (Wallin et al., 2014, p. 1814).

Very little is known about minority populations and ED prevalence, specifically for males of minority status (Hoek, 2002). Of the little research that is available, findings show that binge-eating prevalence was high among African American males when compared with African American females and Caucasian males and females (Johnson et al., 2002). African American women are similar to Caucasian women in their reports of binge eating and vomiting, but African American women had higher reports of misusing laxatives or diuretics (Striegel-Moore et al., 2000).

Unfortunately, there is a belief that EDs do not exist among people of colour; the thought is that larger bodies are the desired ideal for African American and Latin individuals. As a result of this belief, clinicians may not be asking questions regarding body image and eating behaviours given the assumption that this is not a source of distress (Crago & Shisslak, 2003). Additionally, little analysis is available regarding differences between individuals within the same ethnic group. Most studies compare minorities with Caucasians; thus, research in this area is needed to better understand ED pathology in non-Caucasian individuals (Becker, 2007).

EDs are thought to be ‘culture bound’ illnesses that are specific to Caucasian individuals living in Western environments (Prince, 1985). There are reports of EDs being present and increasing in Japan, an affluent, non-Western environment (Pike & Borovoy, 2004). In fact, ED
rates in Japan are thought to be similar to rates in Western countries (Keel & Klump, 2003). Thoughts that EDs may be attributed to ‘culture change’ instead of being ‘culture bound’ are emerging with the contemplation that, as a result of globalization and exposure to more Western ideals, non-Western countries are beginning to show signs trending towards ED development (Nasser, 2009).

EDs have the highest mortality rate of any mental health concern, with an estimated 10% of people with AN dying within ten years of onset (Crow et al., 2009; Harris & Barraclough, 1998; Nielsen, 2001; Sullivan, 2002). However, this number may be an underestimate since long-term follow-ups used to determine mortality are only used for individuals who warrant ongoing clinical attention. Furthermore, death certificates may not accurately label cause of death as being the result of an ED (Norris et al., 2011). While suicide and substance abuse are the most common causes of deaths related to EDs, other related causes of death are cancer, cardiovascular issues, acute gastric dilation, and pancreatitis (Norris et al., 2011).

Fortunately, death is not always an outcome, but the medical complications resulting from ED symptoms are significant. Individuals may experience circulatory changes leading to delayed gastric emptying. This causes discomfort, constipation, and an impaired sense of hunger and satiety which makes re-nourishing more difficult (Chial et al., 2002; Strumia, 2005). Additional issues include dental problems from frequent vomiting, bone density loss, stunting of height, brain atrophy, and cardiac arrhythmias (Birmingham, 2004; Frydrych et al., 2005; Katzman, Christensen, Young, & Zipursky, 2001; Mehler, 2010). Furthermore, if severe EDs present between the ages of 10 to 15 years of age, it can result in a 25-year reduction in life span (Harbottle et al., 2008).
Beyond the physiological issues, psychological consequences also warrant attention. Obsessive thoughts and behaviours, hoarding, isolation, and mood swings, or general low mood, are common with EDs. Essentially, the quality of life for someone diagnosed with an ED is poor. And adolescents are not the only ones impacted by the ED.

When an ED is present, family dynamics change. Many families reorganize themselves around the illness with the intention of not making the ED worse (Eisler, 2005). Mothers can also be dealing with conflict between siblings thanks to the ED, as well as distress caused by unhelpful comments made by well-intentioned family members (Gilbert et al., 2000; Jasper & Boachie, 2007). Hillege et al. (2006) reported that many parents (mothers)\(^1\) felt isolated, helpless, and guilty. They also found that parents experienced financial hardships because they had to reduce or cease working to care for their child (Hillege et al., 2006).

Current treatments are generally based on studies of Caucasian females. The evidence for intervention and recovery rates regarding outcomes for males and other less-common ED groups is less available. Early identification and interruption of symptoms are crucial in order to prevent the various consequences of EDs; however, because of problems with ED identification, adolescents may be diagnosed when the ED is already well established, making weight gain and interruption of binge-purge behaviours far more difficult. Mothers experience many challenges, among them guilt and shame, for not having noticed the ED previously, or for not having

\(^1\) While the study utilized the word ‘parents,’ it had nineteen mothers and three fathers. For this reason, I have added in brackets that a majority of those reporting their experiences were mothers. Throughout this paper “parent(s)” will be italicized to bring emphasis to the language and remind the reader that it is predominantly women/mothers in this role.
advocated for their child soon enough. If the ED has been present for an extended period of time, the family may have reorganized in order to live with the ED behaviours and minimized any conflict resulting from these behaviours.

**Dominant Explanations for Eating Disorder Development**

The dominant explanations for ED development are essential to explore in order to understand the world that mothers enter into with their children. Treatments for EDs are informed by explanations of development, producing both positive and negative consequences for mothers. This section attempts to paint an overall picture of the world that mothers are entering into and that service providers work within.

Table 1.1 portrays the various dominant current explanations for ED development. The purpose of this table is to give a brief overview of some thoughts about ED etiology. It also emphasizes the variety and complexity of existing explanations for the genesis of ED. There is no consensus understanding for EDs.
## Table 1.1  Explanations for Eating Disorder Development

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<td>- Messages on obesity creating fat-phobia</td>
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<td>- Peer relationships</td>
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<td>- Friends’ eating habits, peer pressure</td>
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<td></td>
<td>Familial</td>
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<td></td>
<td>- Family dynamics</td>
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<td>- Enmeshment &amp; the psychosomatic family</td>
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<td>- Marital conflict</td>
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<td></td>
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<td>Blodgett Salafia et al., 2014</td>
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<td></td>
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<td>Bruch, 1979</td>
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<td>Douglas, 2002</td>
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<td></td>
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<td>Ford et al., 2011</td>
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<td></td>
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<td>Haworth-Hoeppner, 2000</td>
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<td></td>
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<td>Becker et al., 2002</td>
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<td></td>
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<td>Chou, Prestin, &amp; Kunath, 2014</td>
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<td></td>
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<td>Dohnt &amp; Tiggemann, 2006</td>
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<td>Dunn &amp; Bratman, 2016</td>
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<td>Field et al., 1999</td>
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<td>Haworth-Hoeppner, 2000</td>
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<td>Latner &amp; Stunkard, 2003</td>
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<td>Li, Min, &amp; Belk, 2008</td>
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<td></td>
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<td>Nilsson et al., 2007</td>
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<td>Nishizono-Maher, 1998</td>
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<td>Pike &amp; Borovoy, 2004</td>
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<td>Puhl &amp; Heuer, 2010</td>
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<td>Shirakabe et al., 1985</td>
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<td>Silversides, 1999</td>
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<td></td>
<td></td>
<td>Simpson &amp; Mazzeo, 2017</td>
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<tr>
<td><strong>- The role of mothers and attachment (intrusive, inability to interpret child’s needs)</strong></td>
<td>Hooper &amp; Dallos, 2012</td>
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<tr>
<td>- The role of fathers (absent, distant)</td>
<td>Minuchin et al., 1978</td>
<td></td>
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<tr>
<td>- Family engaging in diet culture</td>
<td>Pike &amp; Rodin, 1991</td>
<td></td>
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<tr>
<td>- Fat phobic for their children, governing food choices</td>
<td>Rowa et al., 2001</td>
<td></td>
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<tr>
<td>- Mothers’ body image/dieting behaviours</td>
<td>Schofield et al., 2014</td>
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<tr>
<td><strong>Critical</strong></td>
<td>Tasca, 2014</td>
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<tr>
<td>- Social class (upper-middle)</td>
<td>Ward et al., 2000</td>
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<tr>
<td>- Marketing of healthy food as expensive</td>
<td>Bordo, 2003</td>
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<tr>
<td>- Striving for betterment, upwards mobility, or maintaining high social class</td>
<td>Darmon, 2009</td>
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<tr>
<td>- Education and gender norms clash/conflict</td>
<td>Edwards, 2007</td>
<td></td>
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<tr>
<td>- Underachievement in education is encouraged due to pressure on child rearing for women</td>
<td>Gremillion, 2002</td>
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<tr>
<td>- The do it all woman: career and motherhood</td>
<td>Katzman, 1997</td>
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<tr>
<td>- History of control over female body</td>
<td>Lawrence, 1984</td>
<td></td>
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<tr>
<td>- Fixation on body image prevents women from advancing educationally (media as patriarchal tool)</td>
<td>Lester, 1997</td>
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<tr>
<td>- Patriarchy, consumerism, and the illusion of safety if the body looks a certain way</td>
<td>Moorey, 1991</td>
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<tr>
<td>- ED forming as rebellion from societal or patriarchal norms</td>
<td>White, 2015</td>
<td></td>
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<tr>
<td>- Power</td>
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<tr>
<td>Psychological</td>
<td>- Attempting to gain control in an uncontrollable world/situation</td>
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<td></td>
<td>• Development due to traumatic events and/or aversion to sexuality</td>
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<td></td>
<td>• Dysfunctional cognitive processes</td>
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<td></td>
<td>• Poor emotion regulation due to unmet emotional needs (linked to attachment)</td>
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<td></td>
<td>- Confusion of bodily sensations (hunger, fullness) with emotions</td>
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<td></td>
<td>• Stimulus-response learning</td>
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<td>- Positive comments when weight loss achieved</td>
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<td></td>
<td>• Individual personality factors</td>
<td></td>
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<td></td>
<td>- Rigid, perfectionistic, impulsive</td>
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<tr>
<td>Genetic &amp; Biomedical</td>
<td>• Appetite regulation genes</td>
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<td></td>
<td>• Serotonergic and dopaminergic genes</td>
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<td></td>
<td>• Family genetics</td>
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<tr>
<td></td>
<td>• Hormone functioning</td>
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<td></td>
<td>• Bacteria in individual with ED</td>
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<td></td>
<td>• Neuroimaging</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- People with EDs have structurally different brains</td>
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<tr>
<td>Biopsychosocial</td>
<td>• All of the above play a part in ED development</td>
<td></td>
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<tr>
<td></td>
<td>• Adolescents themselves with ED had many thoughts on onset causation</td>
<td></td>
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</tbody>
</table>

Breuer, 1957
Caparrotta & Ghaffari, 2006
Dolhanty & Greenberg, 2007
Everill et al., 1995
Fairburn et al., 2007
Hewitt et al., 1995
Lang et al., 2014
Walsh, 2013
Culbert et al., 2010
Kleiman et al., 2015
Lipsman et al., 2013
Strober et al., 2000
Trace et al., 2013
Haworth-Hoeppner, 2000
Nilsson et al., 2007
Rikani et al., 2013
Multiple and shared causes in ED development

- Genetic predisposition towards anxiety, which leads to high perfectionism. This high perfectionism is endorsed and promoted by the familial and environmental spaces that the youth functions within, leading to ED development.

- Many interconnected factors seen in ED etiology research, thus the multi-factorial explanation
Exploring explanations for ED development can be overwhelming. One can argue that environmental, familial, critical, psychological, and biomedical explanations are all relevant to understanding ED development. Selecting just one or two perspectives to shape the explorations in this study seemed inadequate.

I wonder what impact this proliferation of explanations and helping options has on mothers? If as a clinician and researcher I am desperate to make sense of a complex illness, a mother with emotional ties to her child must be even more confused and worried.

Initially, mothers were viewed as the cause of the illness, leading them to be separated from their child during treatment. Currently, the thought is that parents do not, on their own, cause EDs. We now believe that there are many factors that, when combined, create a higher likelihood for ED development.

The biopsychosocial model (BPSM) attempts to create a broad and flexible way of understanding EDs; however, it is not without its critics (Benning, 2015; Borrell-Carrio, 2004; McLaren, 1998). Some have argued that the BPSM model is not based on an integrated theory. It has “yielded scattered lumps of information that do not relate to each other in any coherent sense” (McLaren, 1998, p. 91) and can lead to service providers to feel “paralysis by complexity” (Ghaemi, 2010, p. 82).

**Overview of Current Treatments for Children and Adolescents**

Treatments for EDs have changed drastically over the years. One of the most significant changes has been the inclusion of mothers and fathers in treatment, although it is mothers who are most present (Hughes et al., 2017). *Parents* were historically seen as the cause of ED development, thus a “parentectomy” took place whereby *parents* were removed from treatment because they were viewed as interfering with the child’s development (Crisp, 1980; Gull, 1997;
Silverman, 1997). This view changed when Salvador Minuchin’s studies showed that mothers and fathers were necessary to include in order to interrupt patterns of family behaviour that had resulted from the ED being present in the family (Le Grange & Lock, 2005).

More current research shows that including mothers and fathers leads to better treatment outcomes (Godart et al., 2012). In addition, given that the ED population has a high treatment drop-out rate, involving mothers and fathers, who are often motivated to see their child recover even when the child may not be, may lead to better outcomes (Pisetsky et al., 2016). Studies show that excluding mothers and fathers from the treatment process leads to a delay in recovery, in turn making it more likely that their child will carry the ED into adulthood (Eisler et al., 1997).

Table 1.2 outlines treatments and their outcomes for adolescents with an ED. Some treatments involve mothers and fathers extensively, while others involve them quite minimally. This is not intended to be an exhaustive account.
## 1.2 Current Treatments for Children and Adolescents

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Description</th>
<th>Outcomes</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Family-Based Therapy</td>
<td>▪ Manualized for AN &amp; BN</td>
<td>▪ Two-thirds recovered at the end of treatment</td>
<td>Le Grange &amp; Lock, 2007</td>
</tr>
<tr>
<td>(FBT)</td>
<td>▪ Agnostic stance towards ED development</td>
<td>▪ 75–90% are fully weight recovered at five-year follow-up</td>
<td>Lock, 2005</td>
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<td></td>
<td>▪ Externalizes illness</td>
<td>▪ More recent reviews state</td>
<td>Lock &amp; Le Grange, 2013</td>
</tr>
<tr>
<td></td>
<td>▪ Therapist empowers parents with refeeding child</td>
<td>35–50% recovered at end of treatment</td>
<td>Le Grange et al., 2017</td>
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<tr>
<td></td>
<td>▪ Three phases over 6-12 months (20 sessions)</td>
<td>▪ FBT is effective for 40% of the targeted ED population, which means 60%</td>
<td>Rienecke, 2017;</td>
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<td></td>
<td>▪ Involves a family meal (Phase 1, Session 2)</td>
<td>has limited or no response</td>
<td>Sepulveda et al., 2010</td>
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<td></td>
<td>▪ Entire family present, including siblings</td>
<td>▪ Best for families who, at baseline, have low expressed emotion</td>
<td>Forman et al., 2011</td>
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<td></td>
<td>▪ Single-parent families may benefit from 12-month treatment versus 6 months</td>
<td></td>
<td>Lock, 2015</td>
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<td></td>
<td></td>
<td></td>
<td>Lock et al., 2015</td>
</tr>
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</table>
<pre><code>                                                                                                                             | Le Grange et al., 2017                                                   |
                                                                                                                             | Eisler et al., 1997                                                     |
</code></pre>
| 1.a. Separated-FBT (S-FBT) | ▪ Similar to FBT (conjoined) above, but differences are:  
▪ Parents seen separately from child due to high expressed emotion or child’s behaviours interfering with session  
▪ Child receives supportive therapy by same clinician as parents | ▪ 60% have good or intermediate outcome post-treatment | Eisler et al., 2000  
Hughes, 2014  
Le Grange & Eisler, 2008 |
|--------------------------|-------------------------------------------------|--------------------------------------------------|---------------------|
| 1.b. Parent-Focused Therapy (PFT) | ▪ Same as S-FBT, except:  
▪ Child meets with nurse for medical monitoring and mental status check  
▪ No family meal session | ▪ PFT and FBT had no significant differences in remission outcomes, yet PFT brought about remission quicker than FBT | Hughes, 2014  
Le Grange et al., 2016 |
| 1.c. Multi-Family Therapy (MFT) | ▪ About 6 families meet altogether  
▪ Varied frequencies reported for sessions (some full day for four days concurrently, others bi-weekly for full day)  
▪ Various different groups throughout the day  
▪ Follow 3-phase outline in FBT | ▪ Low drop-out rates  
▪ Reduces parent isolation  
▪ Reduces stigma | Scholz & Asen, 2001  
Dare, 2000  
Gelin et al., 2015  
Le Grange & Eisler, 2008 |
| 1.d. Cognitive Remediation Therapy (CRT) | - Used in addition with FBT  
- CRT focuses on the thought process instead of the thought content via use of games/puzzles  
- Reflect on how individual and families think in order to bring about behaviour change  
- 10 sessions, 45 minutes in duration, once or twice weekly | - Relatively high satisfaction from clients and family  
- Minor changes reported in cognitive flexibility | Lask & Roberts, 2015  
Lock et al., 2017  
Wood et al., 2011 |
| 1.e. Emotion-Focused Family Therapy (EFFT) | - Used in addition with FBT  
- Parent becomes child’s emotion coach for emotion processing  
- EFFT aids in the development of emotional self-efficacy so ED symptoms not needed for emotion regulation  
- Three stages that work in tandem with the 3-phases in FBT  
- A 2-day workshop developed only for parents to teach emotion coaching | - Testimonials from parents of EFFT are positive  
- For the workshop, parents felt empowered, their feelings of self-efficacy improved | Lafrance Robinson et al., 2016  
Robinson et al., 2015 |
| 1.f. Dialectical Behaviour Therapy (DBT) | • Addresses maladaptive ways individuals with ED regulate their affect  
  • Child and parent both learn DBT skills  
  • Has core modules of mindfulness, distress tolerance, emotion regulation, and interpersonal effectiveness | • Limited results: one study conducted in intensive outpatient therapy setting, three evenings a week for about four hours, for seven to eight weeks, saw significant weight restoration | Federici & Wisniewski, 2013  
  Johnston et al., 2015  
  Safer et al., 2001 |
|---|---|---|---|
| 1.g. Intensive Parent Coaching (IPC)  
  – Specific for AN | • By fourth FBT session, if child has not gained 2 kg, then IPC is added to FBT  
  • IPC is a three-session intervention, added to the 20 FBT sessions  
  • Parents (without their child) meet with clinician  
  • Have a second family meal after the three added sessions | • Children catch up to those who gained weight within the four sessions  
  • Without IPC, 75% of children would have had a poor outcome  
  • IPC sessions improved the self-efficacy of mothers who had late weight gain responders | Lock et al., 2015 |
<table>
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<tr>
<th>Adolescent-Focused Therapy (AFT)</th>
<th>Cognitive Behavioral Therapy – Adolescents (CBT-A)</th>
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<tbody>
<tr>
<td>Manualized therapy</td>
<td>Three stages over six months</td>
</tr>
<tr>
<td>Three phases</td>
<td>Collateral sessions with parents similar</td>
</tr>
<tr>
<td>Focuses on symptom cessation</td>
<td>to AFT (one 1-hour assessment, and eight</td>
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<td>through exploring themes that</td>
<td>15-minute collateral sessions)</td>
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<tr>
<td>arise in adolescent development, such as autonomy</td>
<td>Addresses distorted thoughts, implements</td>
</tr>
<tr>
<td>Adolescents learn to identify and tolerate emotions as well normalized eating</td>
<td>normalized eating through the use of real-time</td>
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<tr>
<td>Parents meet with therapist (collateral sessions) eight times over the course of treatment to update on progress and developmental needs</td>
<td>meal diaries</td>
</tr>
<tr>
<td>In long-term follow-up, AFT catches up to similar results of FBT-AN</td>
<td>FBT-BN is superior to CBT-A for BN; however, at 12-month follow up there are no differences between FBT-BN and CBT-A for BN</td>
</tr>
<tr>
<td>May not be useful for children with high psychopathology</td>
<td>Eisler et al., 1997</td>
</tr>
<tr>
<td>An option for families with high expressed emotion</td>
<td>Fitzpatrick et al., 2010</td>
</tr>
<tr>
<td>For adolescents with parents who are unavailable or who do not wish to participate in FBT, AFT is recommended</td>
<td>Le Grange et al., 2012</td>
</tr>
<tr>
<td>Eisler et al., 1997</td>
<td>Lock, 2010</td>
</tr>
<tr>
<td>Fitzpatrick et al., 2010</td>
<td>Le Grange et al., 2012</td>
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<tr>
<td>Le Grange et al., 2015</td>
<td>Dalle Grave et al., 2013</td>
</tr>
<tr>
<td>Lock, 2010</td>
<td>Le Grange et al., 2015</td>
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<tr>
<td>CBT-A for AN: 40 sessions over 30 weeks. Prior to these, there are two one-hour sessions to prepare individuals for treatment and assess motivation</td>
<td>CBT-A for AN, two-thirds of the adolescents stayed for the entire course of the treatment, improvements in psychopathology were significant, and one third of adolescents gained weight to reach 95% of their ideal body weight</td>
</tr>
</tbody>
</table>
If ED symptoms remain unresponsive to the treatments in Table 1.2, and weight loss persists, or medical instability becomes evident, then an in-patient hospitalization looms. Hospitals monitor the child’s health and resolve any immediate medical risks. Some hospitals may also assist in weight gain if there is substantial weight loss and a refeeding-syndrome risk (Madden et al., 2015). Involvement of the mother and father depends on the hospital. Some hospitals may simply admit acute patients and then discharge them once vitals are stable; others that have a specialized unit may have the adolescents participate in group therapy during their stay once they are medically able to do so. Unfortunately, children that do not respond to out-patient treatment tend to do poorly in in-patient settings (Gowers et al., 2007).

Generally, at 18 years of age an individual is no longer eligible for adolescent services and is put into the adult stream of ED treatment. For adults with an ED, treatment becomes elective, and mothers and fathers no longer play a pivotal role. Difficulties in transitioning from the adolescent to adult systems for ED treatment have been reported (Arcelus et al., 2008; Dimitropoulos et al., 2013).

**Recovery Definitions**

Definitions of recovery are contested. Couturier and Lock (2006) state that defining recovery is a “contentious problem” especially regarding “how narrowly or broadly recovery for [ED] should be defined” (p. 550). One of the most widely used outcome tools for AN recovery is the Morgan-Russell criterion. The general Morgan-Russell outcome criterion organizes individuals’ outcomes into good, intermediate, and poor (Morgan & Russell, 1975). Other studies have defined primary and secondary outcomes in order to determine full remission
The question of individual recovery brings about a discussion of our lived environment. Weight and shape issues are now being called a “normative discontent,” meaning that to not have a concern about weight or shape is considered abnormal. This fact leads to the question of whether an individual can ever fully recover, or if one simply learns to cope with the apparent norms of dieting and body image to which one is exposed daily (Tantleff-Dunn et al., 2011). The ways we are taught to eat by our environment and the new ways individuals and families are taught to eat during ED-treatment are worlds apart (LaMarre & Rice, 2016).

Recovery may not be finite. It may be more of a moving, developing, ongoing process. This last idea is not the most comfortable for clinicians and mothers but may be a reality for individuals with an ED. Often the difficulty with the process of recovery is the need for both psychological and physiological recovery. In many cases, mood improves, making it seem as if the child has recovered, yet their weight still has not reached the level considered to be fully recovered in clinical settings, or weight may increase but the psychological piece of EDs remains equally as strong, or stronger (Brown, 2006).

**The Caregiver Experience**

Despite the crucial role of parents/caregivers in the treatment of adolescent and youth EDs, the literature on the parent experience is limited. There is emerging literature in recent years on the parent experience in the ED context, but in-depth portraits of mothers’ experiences, lived realities, and understandings of living with an ED are rare.
Of the literature that exposes parental experiences, a portrait of their experiences demonstrates that living with, and attempting to interrupt, an ED is incredibly challenging. In general, to witness the physical and behavioral changes in their child can be terrifying and scarring to parents (Cottee-Lane et al., 2004; Hillege et al., 2006; K. Weaver, 2012). Financial and familial changes and challenges have also been reported by caregivers (McCormack & McCann, 2015; Whitney et al., 2005). Overall, the levels of distress reported are high, with some indication that caregivers, particularly mothers, experience clinical levels of anxiety and depression (Zabala et al., 2009).

Literature also illuminates some challenges that parents may experience receiving a diagnosis for their child, accessing appropriate treatment, and surmounting general challenges with various healthcare providers (i.e., feeling blamed or removed from treatment) (Beale et al., 2004; Honey et al., 2008; McCormack & McCann, 2015; McMaster et al., 2004; Sharkey-Orgnero, 1999; Tierney, 2005). Unfortunately, many healthcare providers do not receive adequate education and training in EDs (Lafrance Robinson et al., 2013).
Chapter Three: The Expectations of Mothers

Historically, mothers have been blamed for ED onset and maintenance while fathers, being absent, have received less attention (Bruch, 1979; Maine, 2013; Minuchin et al., 1978). Only recently has the literature begun to shift away from blame towards viewing mothers and (to a much lesser extent) fathers as instrumental for positive change.

This section focuses on normative expectations and customs in developed Western settings. There is no attempt to discuss cultural, racial, or family constitution differences, although “the reality of mothering and of mothers’ oppression varies according to race, culture, and social class” (Freymond, 2003, pp. 38–39). The focus here is on mothers and mothering. Given the nature of the study, this focus is much more thorough than the attention given to fathering.

Mothering

“A mother is a person who seeing there are only four pieces of pie for five people, promptly announces she never did care for pie.” - Tenneva Jordan

I think of how I perceive my own mother: loving, relentless, persistent, caring, concerned, people-pleasing, and self-sacrificing. Her focus was, and still is, on my well-being and she dedicated her energy towards advocating for her children’s needs. Whatever roles she had beyond mother are secondary. I admit that I easily forget she is someone other than my mother and that she exists within a complicated world with multiple roles and expectations. Additionally, she carries a cultural, intergenerational, and personal history. She attempts to meet
all the ideals of motherhood while balancing the demands of other roles (teacher, daughter, friend, sister, wife, woman, etc.).

**Brief History of Mothering**

The expectations of mothering are situated within the social contexts of the times. Lerner (1997) postulated that history helps shape how we live our lives in the present. Unfortunately, we know relatively little about the historical realities of mothering, as poignantly expressed by Rich (1995): “We know more about the air we breathe, the seas we travel, than about the nature and meaning of motherhood” (p. 11).

The Industrial Revolution in the 1700s seems to be the point in time where motherhood gained focus. Fathers were moved out of the home and into factories, leaving mothers as the sole caregivers. Prior to the Industrial Revolution, the roles of mothers and fathers were to rear their children together, although discipline was more the role of the father (Kinser, 2010, p. 29). When husbands left the home during the Industrial Revolution, women, particularly middle class, Caucasian women, took on the primary domestic and child-rearing responsibility within the home. The Caucasian, middle-class ideal of motherhood remains the narrative of a ‘good mother’ even today. Thus, while women who are financially privileged may find that living up to these ideals of motherhood is unreasonable, for women who are not as economically privileged, these ideals of motherhood are impossible to achieve.

Following on the Industrial Revolution was the “happy homemaker” period of post-World War Two. The image, often depicted in advertisements, is of a mother upholding household tasks, child rearing, and serving her husband, while remaining poised and beautiful.
This is often referred to as the “traditional family” image (Kinser, 2010, p. 26). However, this traditional image was soon challenged in the late 1950s when women began to enter the workforce in increasing rates (Government of Canada, 2015). Mothering morphed slowly from where home and work were in the same location, to where women took on home and childcare duties, to where women had more opportunities for work but remained tethered to the responsibilities of mothering.

**Mothering as Natural**

The female body carries the message and expectations of motherhood. The critique from feminist scholars of “patriarchal science” has focused on the belief that women “are born with a built-in set of capacities, dispositions, and desires to nurture children; hence, mothering comes naturally to women” (Hall, 1998, p. 59). The expectation is not only that women should take on mothering, but that being a mother is instinctual, or comes with ease, to a woman. For example, the bonding anticipated to take place during breastfeeding (Thomson et al., 2015) reinforces these expectations. At the very beginning of the mother role, feelings of guilt and shame concerning the body if they cannot satisfy such expectations are present. These feelings are also present when a woman is unable to become pregnant, or has difficulty carrying a child. Mothers may begin their mothering with feelings of inadequacy purely based on their body’s functionality.

The explanation of mothering as a natural experience perpetuates the isolation felt by women. When struggles arise, there is a sense of failure as a result of the assumption that the mother role is instinctive and automatic. The expectation of mothering as natural leads to the
idea of it being unskilled work. Feminist historians argue that “motherhood is primarily not a natural or biological function; rather it is specifically and fundamentally a cultural practice that is continuously redesigned in response to changing economic and social factors” (O’Reilly, 2004, p. 5).

**Mothering as an Institution**

The idea of mothering as an institution was highlighted by Adrienne Rich in her seminal work, *Of Woman Born: Motherhood as Experience and Institution* (Rich, 1995). Tied to the idea of mothers’ bodies and breastfeeding shame comes the linkage to mothering supervision being a professionalized role. The institutional perspective explains that mothering needs to be improved and monitored by male-dominated medical expertise. This perspective leads to women receiving the message that they are “incapable of raising their children healthfully” (Apple, 2006, p. 15); thus pamphlets, books, and online material are created by professionals. In addition, Porter (2010) explains that this institution of mothering is made up of societal expectations dictating how a mother is expected to behave and to interact with her children. These expectations are then disseminated through mass media. The result leads to a “widespread acceptance of the current state of expert ideologies concerning child rearing and maternal obligations” (Macdonald, 2009, p. 413).

A mother who acts contrary to these expectations is viewed as a non-competent or non-compliant mother in the eyes of professionals (Porter, 2010). With mothering becoming a public concern, mothers begin to feel critiqued and judged. This judgement pressures mothers to constantly perform up to the current standards. An example of this pressure is attachment theory
which originally had an exclusive focus on mothers (Lamb, 2000, p. 29). In this theory, Lamb (2000) points out that the focus on mothers makes it almost impossible for others, including fathers, to be seen as important. This led to the idea of “maternal gatekeeping” (Lamb, 1986), whereby mothers fear judgement from others if they need additional supports. They therefore “gatekeep” their role for fear of being seen as inadequate. The impact of professionalizing motherhood, with a focus placed upon mothers to perform in a specific, evidence-based way, along with the pressure to act on these expectations independently, has led to the notion of ‘intensive mothering’ that remains present today.

**Intensive Mothering**

Professional knowledge promulgated by mainstream media emphasized the caregiving role placed upon mothers. This led to what Sharon Hays has called “intensive mothering,” the modern model for mothering (Hays, 1996). Intensive mothering expects mothers to “lavish copious amounts of time, energy, and material resources on the child” (Hays, 1996, p. 8). Essentially, the expectation of intensive mothering is to have “omnipresent availability” and to be a “full-time teacher, primary playmate, and resource for all gratification” (Johnston & Swanson, 2004, p. 507). Of course, this intensive mothering is related to the master narrative of upper-middle-class, Caucasian, able-bodied mothers with financial privilege adhering to this norm. In effect, mothers’ own extracurricular activities revolve around what she can do with her child. This commitment leads to difficulties in being able to perform other roles outside of being a mother. As succinctly put by Büskens (2001): “the problem is not the fact of this requirement but rather that meeting this need has come to rest exclusively, and in isolation, on the shoulders
of biological mothers. This [...] is precisely what is left unsaid in popular accounts of ‘natural’ parenting” (p. 81, emphasis in original).

The gaze of professionals has a profound impact on mothers. This gaze, which motivates intensive mothering, extends beyond professionals to other mothers and becomes an internalized gaze (Sutherland, 2010). The idea of comparison between mothers leads to a sense of competitiveness and a way for mothers to continue to put pressure on themselves: whose mother is dedicating the most time, puts in the most effort, and enrolls their child in the best daycares—who is the best (intensive) mother. An internalized policing manifests itself (Blum, 2007; Sutherland, 2010).

**Blame, Guilt, and Shame**

Guilt and shame are so pervasive that they are considered to be a normal aspect of motherhood (Sutherland, 2010; Warner, 2005). The expectations and pressures on mothers are insurmountable, especially as mothers are thought to be “the main vehicle through which people first form their identities and learn their place in society” (Forcey, 1994, p. 357). What is most unfortunate is that the impossible expectations of intensive mothering inevitably leave women feeling inadequate and fearful of being labelled. Through research interviewing mothers on what it means to be a good mother, Brown et al. (1997) determined that a good mother is required to be “loving and caring, to have ‘never-ending’ supplies of patience, willing and regularly to spend time with her children, and in this time provide her children with the right sort of attention, stimulation, and guidance,” as well as be a calm and relaxed person who listens and communicates well in order to understand her children’s needs (p.189). Furthermore, the good
mother is able to competently discipline her children and teach them how to act appropriately. Thus, the mother must be able to have highly developed skills that enable her to manage these competing demands. Brown et al. (1997) added that “it would also help if she was energetic, creative, and had a sense of humor” (p. 189). More succinctly put by Porter (2010, p.11), a good mother is “exclusively focused on the child” with little consideration for herself.

Mothers experience these responsibilities and the blame individually. Holmes (2006) discusses how this notion of blame functions so that “society does not have to address any of the issues that may be the root of problems. Issues like poverty and domestic abuse go largely unnoticed while blame is surreptitiously shifted from society to the individual mother” (p.51). Mothers’ experience of blame, and the burden that comes with it, is reported in Jackson and Mannix’s (2004) research. In fact, a significant number of psychopathologies in children were attributed to mothering (Caplan & Hall-McCorquodale, 1985). In this regard, the mother’s behaviours are often seen as a cause, rather than a result, of children’s behaviours or ills (Forna, 1998; Maushart, 2000, p. 18).

For mothers, the feeling is that their child’s behaviour becomes a message to others about themselves. They are labelled a “bad” mother by self and others. This labelling is problematic because it precludes “individual assessments of their unique circumstance” and “diverts attention away from mothers’ actual circumstances including their disproportionate responsibility for childcare […] and issues related to race, culture and class” (Freymond, 2003, pp. 47–48). Mothers who are employed believe that their child’s behaviours may be due to their not being
present, whereas mothers who are at home full-time believe it is their ongoing presence and pressure that has contributed to their child’s behaviours (Swigart & Swigart, 1998).

**The Conundrum of Balance**

With more diverse opportunities available to women, different roles compete for their time and attention. Women are increasingly in the workplace. Douglas and Michaels (2004) stated that to fulfil the demands of mothering and a career outside of the home, a woman needs the “combination of selflessness and professionalism that would involve the cross cloning of Mother Teresa with Donna Shalala” (p.5).

Women exist in a body-focused environment. The idea of ‘mom body’ in popular culture describes women who have sacrificed their bodies, or ‘let themselves go’ upon becoming a mother (Bishop, 2009; Dworkin & Wachs, 2004). The additional pressure for women is not only to fight this idea of ‘mom body,’ but to have a superior body, the ‘yummy mummy.’ Being a desirable woman, an unencumbered worker, and an ever-present mother are at odds with each other. Additionally, all these demands must be met willingly and happily. The environment sets mothers up for failure and then blames them for failing. These expectations are especially onerous for women with limited resources, such as single mothers, poorer mothers, or mothers from marginalized populations.

The expectation for mothers to do it all, and do it perfectly and happily, leads to unhappiness (Douglas & Michaels, 2004; Swigart, 1991). “Thus while modern mothers live in a highly differentiated society, the expectation (and often the desire) to remain in perpetual contact with a small child runs counter to the structural requirement of unfettered participation in
multiple spheres” (Büskens, 2001, p. 84). Mothers are pressured to do everything for their children, be all things to all people, do it all well, do it independently, and do it happily.

**Fathering**

Fathers have not been given as much attention in the literature. Clearly how fathering is viewed impacts mothering. Fathers historically had the expectations of providing moral guidance along with the pressures of financial success, and they also had the job to be a model for masculinity for their children (Lamb, 2000). By the 1970s, the “new nurturant father” idea emerged, whereby fathers were encouraged to be more present emotionally and physically in their children’s lives (Lamb, 2000, p.27). This new ideology added to fathers’ roles by increasing domestic tasks such as house-care, as well as greater assumption of child-rearing tasks, or co-parenting (Bocchicchio, 2006; Pleck & Pleck, 1997).

Fathers often felt that taking time off work for childcare might be looked upon unfavourably by their colleagues and might lead to “masculinity harassment” (Cunningham-Parmeter, 2012). But not taking time off meant less time with their families. While two-wage families are now more common, fathers are often still the primary income earners (Lamb, 2000, p. 39). Fathers receive conflicting messages: to be more present for childcare yet remain masculine; to increase time spent with their families, but also maintain a strong workplace presence. The father’s role is one of support. Rehel (2014) calls this fathering role the “manager helper,” whereby fathers are more of an assistant, utilized when requested by mothers.
Chapter Four: Methodology

Narrative Inquiry

Because “there is far more postulated about parents (sic) than by parents (sic) themselves” (Beale et al., 2004, p. 125), it made sense to use a narrative approach in order to hear the stories from mothers regarding their experiences. There is a dearth of literature on the narratives of mothers’ realities when they have a child with an ED. For this reason, I have used narrative inquiry to accomplish my research tasks. Specifically, the basic research question is: “What are the experiences and expectations of women who have a child diagnosed with an ED?”

The first and foremost reason why I used narrative inquiry was to allow the women’s stories to be told in the own words, allowing them the power to tell their story as they wanted it to be told, in order to affirm their life and experiences that may have previously been unexpressed. In other words, to humanize them. Some stories are given more importance than others in our society; thus, my intention for using narrative was for these women to name and claim, and give value to, their own life story as persons whose lived realities may be very different from what service providers and researchers think they know (Cameron, 2015a).

As researchers and as service providers, it is easy to behave as if we have an accurate, and perhaps even superior, understanding of the people who use our services. In the official conversations where important decisions affecting these people’s lives are made, it is our voices, and our determinations about what aspects of others’ lives are important to consider and which behaviours are appropriate, that are privileged (Cameron & Hoy, 2003, p. 2).
It is objectionable that these women are primarily understood and related to in terms of professional assessments and through service providers’ demands, “as cases, […] uncovering personal issues, seeing mothers only in light of their responsibilities for children” (Cameron, 2009, p. 7). Thus, narrative inquiry shed light on an untold area of these women’s lives.

Additionally, there is value in understanding how others live their lives under challenging circumstances, particularly as it is understood by the mothers who are living this reality. Their stories have provided new ways of understanding their realities. They help us gain fresh insights into how these women are living their lives (Cameron, 2015a). The lessons from this inquiry will help us understand how these women have made sense of their experience. Professionals (service providers and researchers) tend to focus on the negative, deficits, or the problem, and often forgotten is a view of the person as a whole. Narrative allowed these mothers to focus not just on the problem and the negatives in their lives, but also the joys, the lessons learned, the strengths, and the humor, aspects often ignored or unacknowledged by researchers and service providers.

This study used narrative inquiry to gain rich information into the experiences, expectations, realities, and lives of mothers of children diagnosed with an ED. As I tried to move away from the assumptions that are been placed upon mothers as a ‘means to an end’ in treatment, and towards viewing these women as whole beings, narrative inquiry was a logical strategy. Narrative inquiry steers “clear of mining the data for themes and the danger this has to depersonalize and decontextualize the stories from the participant” (Maple & Edwards, 2009, p. 35). Stories are ways in which individuals create meaning, and help the narrator make sense of themselves through difficult or atypical events in their life (Riessman, 2008). By communicating
these events to listeners, they make sense of their own experience (Riessman, 2008). Narrative inquiry “at its core is a focus on the study of experience as it is lived” (McMullen & Braithwaite, 2013, p. 92).

Narrative methods are interpretative. Interpretation applies to how the research question is framed, how the participants are selected, and how the data is gathered of data, as well as to the interpretation and representation of the data (Josselson, 2006). Shank (2006) discusses the important differences that an explanatory model—a model typically used in the ED world that tends to have an undertone of blame—has when compared with an interpretive way of understanding phenomenon. Shank (2006) uses metaphors of magnifying glasses and lanterns to discuss the difference. In explanatory modes, the research uses a magnifying glass in an attempt to get a precise view of the lives of individuals or groups. In this mode the goal is to “see the world with as little distortion as possible and explain it with some degree of detachment” (Ospina & Dodge, 2005, p. 146). In the narrative or interpretive mode, the idea is more of using a lantern to “bring clarity to dark places,” allowing for new insights and “reconcil[ing] meaning where it was not clearly understood before” (Ospina & Dodge, 2005, p. 146). Thus, in a narrative approach, the assumption is that meanings of certain events are understood through experience and practice, and those meanings are conveyed through language.

McMullen and Braithwaite (2013) discuss the elements that, when taken together, define narrative as

People (characters) who act (events) in space and time; typically, across a sequence of events (temporality). The narrative form (structure) is said to hold the
content together (what the story is about – its plot) and sequentially arrange the story units (orientation, complication, resolution, closure) into a more or less coherent whole. (p.94)

I have sought to understand how mothers (characters) understand themselves, their roles, and their expectations, focused on the period of time when an ED emerged in their child (event and temporality). Things that were considered through the narrative method were intention and language usage. What events are discussed? Who is this story for when being told and what is its purpose? What is being left out of their story that might have been included? I have also considered how these events were told and why they were arranged in the way that they were told, as well as what the story intended to accomplish (Riessman, 2008). Because narrative stories “do not merely describe what someone does in the world but what the world does to that someone” (Mattingly, 1998, p. 8), I have also considered and explored what it may have felt like to be in the world that these mothers had entered into.

The research area of EDs is typically carried out using a medical framework. Much of the ED research uses questionnaires and structured interviews as methods of investigation. While these are useful methods, they tend to create a disjointed and incomplete picture of human experience, since participants may only respond to the questions that were asked. This strategy and practice can result in the creation of typologies and categories. In addition, there is a risk of privileging the researchers’ accounts over the actual experiences and perspectives of the participants (Saukko, 2000).
WOMEN’S NARRATIVES: COPING WITH CHILDREN’S EATING DISORDERS

Narrative inquiry was selected because it allowed me to view these mothers and women as whole beings, allowing their stories to be conveyed how they wished. The comparisons between those interviewed can be made in order to reveal patterns and any similar themes in stories, while still keeping the story rich with personal data and not discrediting the individual.

Participants, Sampling, and Recruitment

I interviewed 10 women who identified as mothers to children who had been diagnosed with an ED. These women interviewed would have been, or currently still are, receiving service at a community-based ED clinic. There were no specifications regarding the type of treatment received at the community-based ED clinic, or whether or not treatments were completed, since this study was about the mothers’ experiences and realities.

The participants’ ages ranged from early 40s to mid 50s. Two of the 10 women were still working at the time of the interviews. One woman was working part time. The remaining seven women were on a leave or not employed. Three of the 10 women were divorced. The remaining seven women were all married. Three women had one child. Five women had two children. Two women had three children. The children diagnosed with an ED ranged in ages from 14 to 23, with the average age being 16.4 years old. These women reported being active in treatment anywhere from 2 months to 24 months. None of the 10 women identified as a minority, although one woman would be considered a visible minority based on ethnicity. However, this participant did not identify with the minority label.
A non-ED staff (administrative staff) at the community-based ED clinic gave all women coming to the ED clinic with their children a flyer that asked women if they were open to hearing about the study (Appendix A). Women were told they could sign or not sign the agreement to learn more about their participation in the study. Signing the form did not mean the individual was agreeing to participate in the study. Regardless of whether women signed or did not sign the paper, they were instructed by the non-ED Staff to seal it in the accompanying envelope to ensure confidentiality. Once I had obtained the sealed envelopes, the women who signed the form and wrote their contact information down to hear more about the study were contacted. After an explanation of the research and participation requirements, women were given the option to agree to participate or not in the study. The individual’s participation (or non-participation) in the study was not shared with anyone at the community-based ED clinic.

Data Gathering Methods

Although my research had a particular focus of study, “narrative interviewing necessitates following participants down their trails. Giving up the control of a fixed interview format […] encouraged greater equality (and uncertainty) in the conversation” (Riessman, 2008, p. 24). Given that narratives do not have a defined structure or a set list of questions to be answered, one broad question was asked of the participants for them to consider when beginning their story (see Appendix B). I asked the participant: “If I were to make a movie about you during the time of the ED, what would be some key events or things that would need to be in this movie?” Another question that I asked was, “Tell me about your life over the ED’s timeline.” These general questions allowed participants to answer the question as they interpreted their
‘beginning’ of the story. Additionally, the questions are not nearly as important as the researcher’s stance (Riessman, 2008). For this reason, I engaged in active listening, which allowed me to be fully present and to encourage women to share their stories.

Riessman (2008) discusses how these grand-tour questions can be daunting for participants. They may find it challenging to develop and share a lengthy story with a new person. While many women in this inquiry did not have this challenge, I did have a list of probing questions to facilitate the beginning of their stories, or to further the narrative. Some probing questions that I asked were: “How did you first become aware of...?”, “Tell me what happened when...,” “Can you remember a particular moment when...?” and “What about that moment makes it stand out?” (Riessman, 2008, p. 25).

Evaluative questions were also used in order to understand certain specifics, gained from the literature review, about the role of mothering a child with an ED. As it is “preferable, in general, to ask questions that open up topics, and allow respondents to construct answers in ways they find meaningful” (Riessman, 2008, p. 24–25), I asked probing evaluative questions, based on the literature review, to hear how they felt they were experienced as mothers of a child with an ED, and how that affected them.

Last to be mentioned, but first to be completed, was the collection of demographic information. Information collected included age, relationship status, household members, sexual orientation, ethnicity, and so forth. Additionally, information was collected from the mothers on their child’s ED. These were age of onset, duration of illness, diagnosis, and time spent receiving treatment. The rationale of including demographic information was to get a sense of these
mothers as a group. The demographic information was completed prior to the interviews, in a pen and paper format.

Procedures

Once individuals had agreed to participate in the study, we scheduled dates and places to meet for all interviews. The location of the interview was selected by the participant. Most women were interviewed at their home or their own personal office. Other women asked to be interviewed at the Faculty of Social Work’s private interview room. One participant asked to be interviewed at a library near her house, in which I booked a private room to ensure confidentiality.

Prior to beginning the interviews, the participants were given information about the study and an informed consent to sign. All information regarding the study and the informed consent was reviewed with the participant. Any questions or clarifications that participants had were discussed at this time. The participants also completed the demographic information.

The interviews ranged from 45 to 130 minutes in duration per meeting, but scheduled time booked was 60 minutes. Some women wanted to continue to share their story for longer than the 60 minutes, so the interview concluded at a natural ending point. Eight of the 10 women had been interviewed three times. Two women were interviewed twice. Both women had other commitments or pertinent obligations they had to attend to and could not fulfil the third interview session. The rationale for multiple interviews is to get rich, in-depth data on their experiences. Multiple interviews allowed for opportunities of clarification and expansion of stories. I focused on two participants at a time, completing all two or three interviews, then
moving on to the next two participants. This procedure allowed me to dedicate my attention and focus to familiarizing myself with their interview content.

These interviews were audio recorded. During the interviews I wrote down key words in order to keep track of topics I wished to clarify or expand. I communicated this to the women before the interview so they were aware of what I was writing. Detailed notes were not taken during the interview as I wanted to remain as present as possible for the narrator. I had an interview guide with me for each interview (Appendix B). I ensured this interview guide was “sufficiently flexible to accommodate any new aspects that may emerge from the interviewee” (Bates, 2004, p. 18).

After the initial interview, I confirmed with the participants the dates and locations for the follow-up interview(s). During the time between the first and second interviews I reviewed the participant’s narrative and came prepared to ask questions to probe for deeper explanations or understandings. This procedure was repeated for the third interview. These follow-up interviews were also audio recorded.

All the interviews were transcribed. Following the transcription, I completed a narrative summary of each participant’s story. The story of each participant was given back to them, partly to receive feedback and check for any misinformation or any segments that might identify the participant, but mostly to allow participants to have a copy of, and own, their own story.

**Narrative Analysis and Reflexive Interpretation**

As researchers do not “find narratives but instead [participate] in their creation (Neander & Skott, 2006, p. 297), it was vital that I utilize my personal and professional experiences and
reactions to the women’s narratives as secondary data sources, the first data source being the
women’s narratives (Goldstein, 2017). As “reflexivity is intended to bring awareness to oneself
as a participant in the research” (Goldstein, 2017, p. 149), I made no attempt to try and hide
myself nor my reactions and interpretative process. Every choice that I made as a researcher,
from why I selected this topic to the ways in which I communicated the results, was influenced
by my subjectivity. My analysis was grounded in the stories that women told, but I also utilized
my own experiences and immediate reactions to interpret the stories. Goldstein (2017) states that
the subjectivity of the researcher contributes to the creation of the data gathered and the
interpretations that emerge, and that self-examination is used (and necessary) to create
procedural integrity. The reflexive methodology I utilized was influenced by Alvesson and
Skoldberg’s work (Alvesson & Sköldberg, 2009).

I used a reflective journal to record my thoughts and reactions to the stories, similar to
processes documented by others (See: Goldstein, 2017; Ortlipp, 2008). Journaling took place on
an ongoing basis. I reflected on my research topic: my motivations for engaging in this research,
my own positionality and intersectionality, my own biases and beliefs, my clinical practice
experiences, and reviewed literature. Similar to Goldstein (2017), in my clinical practice “I saw
myself beginning to mimic the cynical and exacerbated attitudes I observed. But over time I
noticed that I did not genuinely feel cynical or exasperated, in fact, I especially enjoyed working
with” women caring for a child with ED (p.152). However, I noticed myself burning out due to
organizational and systemic barriers, coupled with feelings of hopelessness of feeling inadequate
with the support I offered women and families.
I journaled any thoughts that may have occurred before meeting the women in person, reflecting on the email communications for setting up a time to meet. I wondered about the content they would share with me. For example, through my literature review many parents in the qualitative research spoke of the challenges they faced with service providers from various disciplines, so I began to expect that only negative reports from women would be present in the narratives (this was not, in fact, true). I journaled immediately after every meeting. I journaled as I listened to the audio recordings before meeting women for the second and third interviews. And I journaled as I constructed the women’s stories and re-read them.

Sutton and Austin (2015) state that being “aware of the standpoints you are taking in your own research is one of the foundations of qualitative work” (p.227). My own interactions with mothers of an ED child have been in the role of a service provider. For this reason, I needed to engage in reflexive journaling in order to place my own biases, preconceived ideas, and historical experiences front and centre for transparency.

Throughout my journaling, I noted a variety of emotions and a constant challenge of shifting from the clinical lens of explaining and advice giving to one of the curious researcher. Admittedly, this was the hardest work. It is important to note that my own thoughts and preconceptions were not abandoned, but rather I was “honest and vigilant about [my] own perspective” in order to attend to the mothers’ stories with an open mind (Starks & Trinidad, 2007, p. 1376).

The reflexive journaling process was exhausting, and did yield a surplus of information and journal entries that led, at times, to complicated, infinite self-analysis. Finlay (2002) called
this “the swamp”: researchers end up in a space of constant self-reflection and deconstruction so that they lose sight of the research participants and unintentionally move away from developing an understanding of their lived experiences. Reflexivity should not be an “opportunity to wallow in subjectivity nor permission to engage in legitimised emoting” (Finlay, 2002, p.215); rather the reflexive work is to “use personal revelation not as an end in itself but as a springboard for interpretations and more general insight” (Finlay, 2002, p.215).

I adapted Finlay’s (2002) maps for reflexive research practice, more specifically, the introspection map and the mutual collaboration map. The introspection map involves self-dialogue, whereby the researcher’s own thoughts, intuitions, and reflections provide data. Just as Moustakas’ (1990) experiences with loneliness were the genesis for his research, my own experience with burning out, feeling I had nothing more to offer women who were supporting their children, and witnessing their distress led me to this research. I often came back to this process by reminding myself what had prompted me to take on this research endeavour.

The other map I utilized was intersubjective reflection (Finlay, 2002). In this map “researchers explore the mutual meanings emerging within the research relationship […] where the self-in-relation-to-others becomes both the aim and object of focus” (Finlay, 2002, p. 215-216). Here, I examined how the conversations I had with women affected me, and I reflected upon my internal processes that make these reactions emerge. For example, I was often angry hearing about realities these women faced. Hearing their unfiltered struggles and witnessing them attempting to make sense of their experience by often turning inward on themselves ignited my anger as to how unjust it is that women are personalizing these struggles as individual flaws.
My anger was also invoked when women spoke of the challenges they encountered with service providers, but on further reflection I identified this anger as internal shame: I am a service provider, and I have caused distress. This often led me to spiral into problem solving and reliving those feelings of hopelessness I felt as a clinician when I had nothing else to offer.

Overall, the purpose and intention of this reflexive process is not only to serve as data and to provide a way to transparently present how I arrived at my interpretations, but also to bring my expectations and assumptions into awareness so that I could monitor the impact that these reactions had at all stages of the research in hopes of remaining open to the diverse experiences and stories shared by research participants.

**Familiarization of the Data**

In order to remain close to the stories of these 10 mothers, I conducted the complete interviews (initial interview, follow up interview, and final interview) two participants at a time. By keeping my focus on two individuals at a time I was able to remain close and attentive to their stories, as well as to familiarize myself with the data that emerged.

I listened to the recorded interviews several times and kept notes on my analysis in my research journal. I noted not only my thoughts and reactions to the story I had just heard, but also some of the story lines I began to notice, and how the stories were constructed. I also kept track of information and ideas that I wanted to explore further with these mothers in the follow-up interviews.
After the transcription of the narrative stories, I read each story several times in order to notice any common story lines and experiences that emerged (Riessman, 2008). I also continued to keep analytic memos while I read through these transcriptions.

**Narrative Summaries**

Following the familiarization of each individual’s story, I created a summary of their experience of being a mother to a child with an ED. The summary was guided with the questions, “What is this story about?” and “What are the main story lines?” These summaries were, on average, 7 pages in length each. To construct their stories, I listened to the audio recordings several times to locate important moments, concepts, or experiences. These moments were indicated to me through the words women used (“it felt like,” “I needed,” or other evaluative words) or the emotions they expressed (moments when women spoke quickly with anger or frustration, moments when their tone slowed down to indicate something important, or moments when they were tearful). I also utilized my post-interview notes, where I documented what stood out for me following the story I had just heard. From there I took verbatim from the transcripts what women had said and reorganized the excerpts to make a coherent story. These stories were given to the original storyteller (mother) in order to check for accuracy. Women were free to highlight information they wanted included that I may not have originally identified as important. Women were also able to inform me of any misinformation, or information they wanted removed. The women did not have any changes except for some minor dates in their timelines and removing potentially identifying information. Essentially, I presented a slice of these mothers’ realities, which are inherently complex, in order to get a sense of them as people.
Women corroborated the information I deemed as essential through their review of their brief co-constructed stories.

Utilizing the narrative structural analysis, as outlined by Riessman (2008), I explored how the mothers ordered their stories, what story lines were presented, and how the mothers evaluated the events and processes they experienced (Riessman, 2008). Riessman (2008) discusses the search in narratives for “evaluative statements” (p. 89), which may be things such as helpful or positive moments, struggles and challenges, or encounters that were positive or negative. Additionally, I examined how the mothers had constructed their story, specifically the chronology of events. Riessman (2008) suggests examining the “sequence of action, turning point, crisis, [and] problem” (p. 92) as information to pay attention to for analysis. How the mothers used metaphors, humor, irony, and sarcasm in their stories was also acknowledged through the analysis (Riessman, 2008).

I attempted to be transparent throughout this process, especially since how I constructed these mothers’ stories was unique to me; others might construct these stories in different ways (Cameron, 2015b). By having the mothers review and provide feedback on my summation of their stories, I hoped to remain true to the experiences that they had shared in their narrative interviews. Additionally, by making my unfiltered reactions known, and documented, readers may see the reflexive and interpretive process that I engaged in. Of course, “reflective actions occur to some extent within the confines of the researcher’s mind lending them a highly idiosyncratic quality that defies easy description” (Goldstein, 2017, p.154). By providing both
summaries of individual women’s stories and my initial reactions to these stories, the intent was to allow readers a foundation for assessing for themselves my “sense-making” of these stories.

**Searching for Insights Within the Narratives**

This step of the narrative analysis process focused on looking for overarching, broad patterns that emerged through all of the mothers’ stories (Riessman, 2008). In this analytical phase, I searched for similarities within their stories, as well as contrasting information or differences within stories. Things that were considered about the narratives also included the consistencies and inconsistencies that were seen in existing literature (McMullen & Braithwaite, 2013). I embarked on this process by reading through all the narratives and in the margins of the transcripts I would note what sections were discussing and ascribing an emotion or experienced feeling. For example, I would remark in a corner, “the labour is demanding, hard.” Once all 10 narratives were reviewed, and marked up with comments, I would move all the comments from the story margins into a table with women’s names as the header. From there, I grouped content together as to “likeness.” For instance, “constant cooking,” “parenting changes,” “life consumed,” “numerous losses” all lead to the early stages of the storyline: “EDs are overwhelming to live with.” Through further refinement, the outcome is the first storyline (Chapter Six): “It is an overwhelming challenge to live with daily eating disorder demands.”

**Ethics**

To meet ethical standards, I submitted an application to Wilfrid Laurier University’s Research Ethics Board. Additionally, the community-based agency reviewed the proposed study to ensure that the ethics of individuals who have accessed services at this organization are
appropriately considered. Both Wilfrid Laurier University and the community-based agency approved of the research protocol and felt that ethical standards were met. This study followed the ethical guidelines outlined in the Tri Council Policy Statement 2 (Medical Research Council (Canada) et al., 2014).

**Confidentiality, Anonymity, and Informed Consent**

Neither I, nor the community-based ED service providers, knew who had agreed or declined to participate in the study when given the flyer, as it was up to each woman if she wanted to write down her contact information on the flyer or place the flyer back in the sealed envelope unsigned. If an individual did wish to know more about the study, they were to contact me at the information provided on the flyer. After I explained the study, regardless of whether or not they chose to participate, they were assured that this information would not be shared with the community-based ED clinic. Any individuals whom I know personally or professionally were not eligible for the study. This issue did not arise during my recruitment.

Participants had the research project explained to them in detail, and all participants were given the space to ask questions regarding what they were agreeing to. Participants were informed that they had the right to stop the narrative interview if they found the content too difficult or had changed their mind about their participation. Participants were also given pseudonyms, and identifying information was removed to protect their identities.

All data (transcriptions, journals, demographic information, audio recordings) were stored securely and only accessible with a computer password. Additionally, the consent forms and the demographic information were kept separately from the participants’ transcriptions. The
only individuals who had access to the password or information were me, Jennifer Scarborough (PhD candidate), and Dr. Gary Cameron (supervisor). The information in this inquiry will be stored for up to two years, and then electronically destroyed.

**Strengths and Weaknesses**

In general, questions of validity and generalizability “lack relevance in the context of narrative inquiry” since multiple realities exist and the ways in which I understood and interpreted the data are constructed through what the mothers presented to me, and how I made sense of their stories (McMullen & Braithwaite, 2013, p. 95). In addition, the fact that this research was conducted within one agency is a limitation. The community-based agency culture may have affected how mothers had experienced the ED compared with, for example, a hospital setting. Essentially, the stories represented in this inquiry are not reflective of all women’s experiences. Narrative does not seek to be generalizable, but rather to humanize and generate new ideas for future study.

Regarding participants, this study was primarily comprised of “traditional” (n=7) or single (n=3) mothers. Non-traditional households were not specifically the focus of this study as narrative research is not adapted for cross-group comparisons. Fathers were also not explored in this study. Fathers and families of different constellations face a different set of challenges that require separate investigations.
Chapter Five: The Women’s Narratives

These next pages will take you through the stories of 10 women, as well as my own reactions and initial thoughts about these stories. These stories are representations of what each woman wanted to communicate, and how it was heard by me. The women’s narratives are lengthy, and this is intentional. Stories were constructed this way so that the reader has as much of the women’s story as possible. This will allow readers to conclude for themselves aspects of these stories that are important, or to interpret information through their own lens. Additionally, these stories are lengthy in order to privilege the voices and experiences of women.

Each story is followed with an immediate, personal, uncensored, reaction by me. These reactions were recorded immediately after the interviews with each woman. They are not “proof” or “truth,” but rather my initial reactions. I believe my immediate reactions are useful to give readers insight into what I deemed important or challenging and why. These initial reactions have evolved over time, as will be evident at the end of this thesis. These reactions illustrate my interpretive processes for readers. Both the stories and my reactions are intended to ground what is to come in the interpretive chapters.

What is not captured in these narratives is the readiness with which these women were keen to tell their stories, and (in my opinion) without resignation. Answering basic demographics about their children hurled them into telling the story of the genesis of the ED. These stories are long, with each woman’s story being anywhere from 6 to 8 pages. These stories are lengthy so that readers have the same information that I had, so they can hear the stories in full, and
interpret the information through their own lenses. These stories are also lengthy to give readers a sense of the storyteller as an individual.

These stories often started with tears or sighs of exasperation. I also reflect on points where their narratives are particularly detailed, or directions in which their narratives tended to go – stories about their children. While some bits of information regarding their children are included where it appeared to highlight realities that the women faced, much is removed. The tendency to focus on their children leads me to wonder why the detail was so vivid there, despite these women knowing I wanted to hear about their experience, and their realities. I cannot help but wonder if this focus is a result of their tendency not to speak to others about their own truths and experiences. There perhaps was an unstated assumption that others wanted to hear about the “ill” person in question, where the illness resides, rather than from the person who is experiencing and living with the illness all the same, not to mention the one responsible for treatment and remedy.

What else is important to note, but is not included in these stories, is that many of the women spoke about the experience of doing the interviews once we had concluded our meetings. Many of the women spoke about the process as being very validating. They were grateful that they had had the opportunity to share their untold story, to speak without interruption, advice, or assessment. They spoke of the experience as being unique. Frank (2005) states:

One of our most difficult duties as human beings is to listen to the voices of those who suffer. These voices bespeak conditions of embodiment that most of us would rather forget our own vulnerability to…. Listening is hard, but it is also a
fundamental moral act; to realize the best potential in postmodern times requires an ethics of listening. (p.25)

My intention is to help the reader see these women as women, rather than as just mothers, and not to judge, but to react personally to their stories. It is most important that the reader get in touch, and feel what the experience must be like, and what it brings up in us. I conclude this section with an overall reaction to hearing these ten stories.

**Personal Stories & Reactions**

**Christina**

<table>
<thead>
<tr>
<th>Age:</th>
<th>Early 40s</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment &amp; Status:</td>
<td>Healthcare Field, Working</td>
</tr>
<tr>
<td>Marital Status:</td>
<td>Divorced, has a long-term partner.</td>
</tr>
<tr>
<td>Number of children:</td>
<td>1</td>
</tr>
<tr>
<td>Diagnosed child’s age:</td>
<td>15</td>
</tr>
<tr>
<td>Child’s diagnosis:</td>
<td>AN-R</td>
</tr>
<tr>
<td>Duration with the ED:</td>
<td>~6-9 months</td>
</tr>
<tr>
<td>Treatment:</td>
<td>2 months</td>
</tr>
</tbody>
</table>

I felt bad in a sense I was a parent because I wasn’t cluing into what was going on. She’s a night owl, so I thought she was up studying, but she had a whole [workout] routine and weights in her room, then I just noticed different foods [she was] not eating, stopped taking lunches to school, you know, we always used to have, like, ice cream or Oreo cookie dates was our big thing and she just stopped any sweets, I can’t tell you the last time she had chocolate or ice cream.
I remember when it was first diagnosed. I’ve tried crying in front of her, trying to support her, I lash out, I get angry, even last night I’m like, “You’re going to end up in the hospital with a feeding tube down your throat or your nose, do you understand this? This can kill you,” but it’s like talking to two different people. It’s that split personality, talking to two different children, it always comes back to that because it’s just like who am I talking to today? I didn’t know what being a mom with an eating disorder… I’d never dealt with it, because I did it myself, but I never knew how my parents felt.

I tried to be open and honest with her about my past. In my head I’m like “I hope I didn’t foster this,” you know, ‘cause now she has this goal weight that she wants which was actually my goal weight, I wanted to be a hundred pounds was my thing and that’s what she’s telling [the ED clinic] she wants to be. I’ve just always been health conscious; I’ve been athletic my whole life. I’ve just always taught her to be health conscious, when we go grocery shopping “which one should we buy? This one?” Now she’s a label reader, a calorie counter. In my head I’m like, “did I foster this?” She says I didn’t, but it’s hard not to think that way.

There’s a whole bunch of things going on, but now she lives with me. [Child and ex-husband] had a big blow out and she’s been with me ever since, which, I think, is the best place for her, even though it’s extremely frustrating. I’m like, “What more can I do for you?” I don’t know. I’m trying to help her get through this but if she were at her dad’s, I don’t think it would be well received. He made the comment to [the ED therapist about my daughter] “You’re just doing this for attention.” “Well, no, she’s actually been diagnosed with this, so she’s not doing this for attention.” She made a comment about her dad like, “Well maybe he’d come see me if I ended up in the hospital with a feeding tube down my throat.”

Unfortunately, it’s just a bad messy divorce, we don’t communicate, we communicate through [a phone] app. You’re supposed to do family sessions, but we don’t, just because there’s so much tension, and it’s usually week to week and a half [between therapy sessions] and he’s never been to any more, he’s only done the one back in January. He’s never followed up either, so, that’s why I think she’s in a good place. Until he’s on board and they fix up whatever issues
they have, that’s a whole other story. She’s in a better spot with me, which puts my stress level to
the ultimate.

I feel just even my stress level, my general well-being, I feel like I’m on high alert now, just constantly checking on [my child] more so during the day or at home or if I work late. The stress level for sure has gone through the roof. I’m trying to act the same way around her but it’s extremely frustrating when you’re dealing with that other persona that wasn’t involved in your life before, so, it’s like that extra person, it’s weird, it’s kind of surreal. She’s always been a good kid, I’ve never really needed to discipline her pre se, but I feel like I’m actually vocally disciplining her, engaging with her more just because of the frustration with the eating disorder, whereas before [it was] common teenage stuff like clean your room.

It’s even brought stuff out of me too [regarding my own ED history]. I go, “Oh my god I think that’s the year that grandma and [grandpa] split up.” Because my dad was an alcoholic I said, “I actually think it was around that time,” I said “So, maybe that was indirectly a stress on me, that’s why I stopped eating, my parents split up for three years, so, at the beginning of that…” So, it is helping me help her with respect to I’m bringing out my past stuff to try to help her through it. Her big question is, “How did you do it?” and I’m like, “If I knew I would be telling you, but I’m a different person than you are,” like it’s not a quick fix for her, and it’s not a quick fix for me, it’s definitely not a quick fix for anybody going through it and if I could fix it in a heartbeat I would but I don’t know how to.

I have to be on 100% of the time. I feel like I’m always having to be home, there’s obviously a lot more grocery bills, shopping, meal prep, that kind of thing, which indirectly I like to do, but it’s only been two months, but I feel like it’s been a year since she’s been living with me [full time] because it’s just overwhelming. That’s why I said, “I need to go for at least one night.” I go [to the child] “my life has changed a lot too, I’m used to a 50/50 relationship with you because you were with your dad, so, I’m used to staying at [my partner’s] house 50% of the time when you weren’t here, so, and by no means am I making this sound like it’s you’re bad and it’s your fault but we’re all making sacrifices too, [my partner is] used to having me around him 50% of the time.” Last night she made me feel like I wasn’t around, I go, “I’m here every
day, every night,” I said, “the only thing I ask is one night on a weekend I’m going to go stay at [my partner’s] house,” so, I said, “I need that myself.” Just because I’m at [my partner’s] house I said, “I’m more on high alert, why do you think I send you pictures or constantly facetime you?” I’m constantly texting her with my phone if I’m at his house or what not, and I’m usually home first thing in the morning.

I’ve tried to keep up her communication with my ex’s side of the family. [My child] has a cousin who is 12, her aunt, my ex’s sister, and then her grandparents. My parents are still around, they’re in their late 70’s though. My dad was just diagnosed with [a degenerative disorder], but he can still drive and what not, and my mom worked [in a healthcare setting], so they are still an awesome outlet for me. My brother is in [a nearby city] so he’s close by with his family, my sister, she’s in [another country], but everyone kind of knows what’s going on, and then my significant other. People have said they’d help out and I know people have their own lives but even in the last two weeks the ex-in-laws, my ex-mother-in-law, the aunt, I don’t see anyone driving up on days to have lunch with her. They’ve offered and then once they did it and [my child] just had a meltdown, she left school, so, and nothing’s really happened since.

It’s more of a frustrating atmosphere at home. I find myself short fused, especially Thursdays I work 9:30 till 8 and I’m one-on-one all day. I still like my profession, but I want the 8:00 to 5:00 pm job. I feel like I wear many hats. Then when I get home [my child] wants me to be on and I can’t be on, I said, “I can’t” and we’ve talked about this with the social worker at [the ED clinic], I go “I just need to decompress, I need to just sit, stare at my Facebook account, watch some mindless television show for half an hour just do decompress my brain because I’ve had to be on all day,” whereas she’s been missing me. She wants the attention right away, so that aspect is frustrating too. I think she worries about me more. She texts me Wednesday night “Where are you?” I’m just out with my significant other. I just needed to decompress, it’s like, “Are you worried about me?” she’s like, “Yeah ‘cause you’re not home,” like I feel like I have a keeper now. I feel like she’s a toddler now and I feel like I’m monitoring her, I don’t feel like she’s [a teenager], I feel like I’m back to pre-school and watching her every need, whereas teenage years are supposed to be different, I know they’re differently changing and all that, but, I
I feel like I’m micro-managing as I would for a preschooler, rather than letting her find herself as a teen and she has all these dreams.

I don’t have any alone time anymore, I guess that’s a big thing. I miss that, I feel guilty ‘cause I say, “I just want my life back the way it used to be, I want my 50/50 life” and it’s not that I don’t want my daughter but that’s the way it’s been [50-50 for] 10 years pretty much. I only have Fridays off and sometimes Tuesday’s. I quit my job on Tuesdays so I could take her to [the ED clinic]. I used to work in [the city] Monday-Wednesday-Thursday and two Saturdays a month, Tuesdays I was working in [another city] but I quit that so I could drive her to [the ED clinic] on Tuesdays. The intake days [at my work] are Mondays and that’s a big day for me, that’s an 11-hour day for me and I can’t afford to lose that. I need work for the money, [the ED clinic] talked about me going on disability, which I probably could get approved for because I have a child who’s suffering from anorexia, but I will not receive the full income and wages that I’m getting now. EI won’t pay that.

I feel like when I go to my [ED clinic] visits I’m judged. I am a single mom, but they recommend all these things and then we go back every week and a half and it’s like, “well did you try this?” Our morning routine, usually, is I’ll get up first, shower and get ready ‘cause we have the one-bathroom upstairs, while [my child] eats downstairs. They wanted to do meal monitoring, well I don’t have time to sit beside her to make sure she’s eating, and I’m not worried about breakfast because I hear her eating downstairs. Lunch I can’t control because I work 10- or 11-hour or 8-hour days it just depends on the day, but they also want a meal monitor, so we tried getting one of her friends to sit with her at lunch, but they don’t understand what’s going on. So, now she’s not eating lunches. Dinners I’m pretty much either home sitting with her [but when] I’m not at home they wanted me to do, like, facetime with her to make sure that I kind of eat with her while I’m at work but it’s hard because I see patients, so, I only have a couple of minutes in between patients.

Sometimes I feel like they look at me like “Why aren’t you doing more?” I feel like I’m doing the best I can do, so, as I said, could I make her lunch every day? Yes. Should I? Yes, but as I said but then in a sense this just frustrates me and then we’re back to a waste of money and
what not. She’ll just leave it there. “You should get up early, you should sit with her and have
breakfast on your Tuesdays and Fridays off, you should be driving to [the child’s school] and
having lunch with her.” On my Tuesdays day off, I drop her off, I have this meeting, usually it’s
running around, appointments of my own. I feel like a ping pong ball sometimes. [The ED clinic
says] “Well maybe you need to set your alarm clock a little bit earlier so you can get up and have
your shower and sit down with [your child] and have her breakfast” and I’m thinking, “Lady, I
don’t have a time for that.” I need to physically start getting myself prepared for the day, that’s
why I feel like I’m judged sometimes. I’m around her and it’s not like I’m ignoring her totally,
I’m passing her at least 20 times in the morning so I know if she’s eating. I just can’t do any
more than what I’m doing. If I have to get up earlier that’s an extra half hour, [that’s] a lot of
sleep for me, especially if I’m not sleeping at night.

“You need to make her lunch for her.” It gets frustrating, I make her lunch for a couple of
days, so, she’s either throwing it all out or it’s coming back and it’s a waste of food. I’m in the
single mom factor, wasting money, it just makes me angry. I feel like turning to [the ED
therapist] and saying “You know what? I can’t do it anymore; this needs to be on her now too.”
[I stop myself from saying this] because they’re the professionals? It’s going to happen because I
feel like I’m going to snap at them sometimes. I just feel like there’s judgement and I already
feel like I’m doing the best I can do. I keep saying, like “what more?” and I’m on my own here.
What if I end up in a bad spot? Who’s going to take care of her then? ‘Cause I’ll be taking care
of myself; you know what I mean? Like, if I end up in a bed, flat out depressed. I was trying to
do everything at once by just staying with her 100% of the time when this first happened, but
then I realized “this is not good for me” so I told [my child], “I will stay at [my partner’s] house
at least once or twice on the weekend.”

I feel like I’m doing everything I can, but a lot of this can be on her too now, she’s old
enough. If I take 100% of, if something happens and it fails, if I were to take the onus on me,
then that’s not fair to me as well. There are moms taking 100% of the blame. I still need to do
my own stuff and my relationship can’t suffer. “I will go do my kickboxing class and tonight I’m
going to watch the hockey game because you know I like doing that and I’m going to do it at
[my partner’s] house after I make you dinner even though I’m driving here, to there, but I’m still going to go do it” so, otherwise I think if I didn’t do any of that then I might be in a worse situation, you know what I mean? Because I was 100% with her all the time and honestly, I can’t handle it, sometimes it’s depressing being around her […] Like “I need to leave,” “Can I come?” “No, I just need to go on my own somewhere.” There was one time I was at [my partner’s] house and I started driving back, I think it was right around here and I was just teary and then he messaged me cause he thought I was staying for dinner and I’m like, “No, I have to go” and then, so, he was just kind of whatever and then I go, I called him and I’m like, “I can’t even go home right now because I’m crying and I don’t want her to see me like this” he’s like, “just come back here then,” so I go back there but sometimes I just snap, I need a time out… But I don’t think I could ever find that solitude of a time out because even if she’s not with me she’s still with me. [The ED clinic] keep sending me information about taking a leave and collecting disability… but I can’t afford it. I just finalized my divorce and I need the money. It’s already stressful enough, I don’t need to add more stress on me because I’m not going to be able to function to take her anywhere. Indirectly, I’m crying on the inside, but I don’t like to show [my child] that. She’d probably say I don’t show my weakness in front of her. I guess I’m always that strong mom in front of her. I feel selfish, today’s my day off, I should be going to have lunch with her at the school, but there’s some other stuff I need to get done and appointments, and I’d like to go to the gym and do a kick boxing class like I usually do, so, is that selfish of me? I don’t know, sometimes I feel like it is. If I don’t take care of myself, I’m not going to be able to function for her.

Sometimes I just want to take a life break. But the thing is you can’t shut off your mind or your brain from thinking. I have trouble sleeping now and grinding my teeth, I wake up and my head hurts in the morning. Sleep, stress, my own weight loss. I just wanted a break. I love kick boxing in [city], I joined that last year so I’m going to try to do at least two things that makes me feel okay, but if I could go to the gym or do kick boxing and soccer, [just] three things to keep me active. I feel selfish for saying, “I just want my life back.” [It feels selfish] because she’s my daughter so I should be doing everything I can. I feel bad for saying it, but I liked it the
way it was before. I don’t know what the future holds, I can’t even book a trip because I don’t know if she’s going to be well enough to go. We usually go to Mexico in the summer, my friends just booked that last week. [Friends and family are] always checking in but I think it’s almost time for me to go to my medical doctor and say, “I need a note because I need some time off work.” People keep saying it’s going to get worse before it gets better. I’m like, is it not worse already? Like what more can happen? I can’t take anymore.

Listening to Christina. At the beginning of our interviews, I recall Christina saying that she felt she didn’t have much to contribute but wanted to help anyone who may go through this experience. She and her daughter had only been in ED treatment for about two months. As a result, there was initially a bit of “I don’t know” or “I’m not sure” responses to my questions. I remember struggling to engage her in long monologues. I recall wondering, “How will I engage Christina and have her express more to me about her experience?” When I step back and look at the other events and situations that are not captured verbally in the interview, then her reality becomes a bit clearer to me. Our first meeting had to be cancelled because Christina had an injury that affected her mobility, and she therefore could not come to meet me (in fact, she couldn’t even get out of bed). After a few reschedulings, we met a second time. Her ex-husband had decided to remove all of their daughter’s items from his house and put them into storage, causing Christina to have to explain to her daughter that her father does not want a relationship with her right now. On top of all of this, she was working, and her daughter was continuing to lose weight. The reality for Christina was that her life’s challenges are beyond just the ED, and I imagine the time for self-reflection or even pausing to think about her own self in all this was just not possible to do. My impression was that she is just trying to function, trying to do it all.
And despite trying to do it all, she also said numerous times that she felt her daughter would eventually go to an inpatient hospital. I feel her immense helplessness in these moments, when she conveys all she’s done and the barriers she’s up against.

My analytic notes completed post-interview with Christina were filled with adjectives of my interpretation of her presentation: strong, tough, frustrated, not tearful. I thought of myself as a clinician, meeting with Christina, and what this would have meant for her. For me, I would have seen her as, “Oh she doesn’t get how serious this is,” or, “She isn’t distressed enough about her kid being sick.” Then I step back and think to myself that she is in the role of being all things to her child, with little support for herself. She mentions not having time for things, and I imagine that means time to fall apart. She is her own support, and from our interviews it appears that she is white-knuckling it through this ED experience, just trying to make it through. The ED team isn’t providing her with the support she needs. It’s likely not available. I think back on my own judgement of Christina for not being sad and crying in the session. I remember thinking, “So many of the moms I have interviewed have just broken down and begun to cry. How come Christina doesn’t? Her daughter is actively losing weight, what is going on here?” I recall this thought and processed it further. What the hell am I expecting from her right now? Why do I need her to prove to me that this is distressful by crying? Why does she have to prove to me that she cares through breaking down?

When Christina talks about having “no more tricks” in her bag to support her daughter, I become self-referential and think to myself what it is like to have “no tricks left.” I can only know this through a clinician’s role, and how hopeless it feels to have no idea how best to
support a family anymore, and just to resign oneself to monitoring its demise in sessions. For Christina, this to me is where she is at: having no more tricks, she carefully monitors her daughter’s weight loss, readying to go to inpatient treatment.

Of interest in writing Christina’s story is that while she tries to understand and identify with her daughter, I am trying to identify and understand Christina herself. If for me trying to understand her reality is proving to be a struggle, and such a mental effort (case in point is writing this very section, it has taken me numerous tries), then I can only imagine how tough it is to try to understand and support someone you love, and have known all your life, who has changed drastically.

When meeting with Christina, my own urges to give her support and advice were prominent, especially since she had only been to a few sessions at the ED clinic. I am trained to look at deficits, interpret information, and assess content. I’m trained to fix, or at least offer suggestions to help Christina fix. I imagine for Christina to have to stop parenting the way she knows how is incredibly hard. Just as it was hard for me to unlearn my clinical social work roots during this research, it’s hard for her to unlearn the way she’s parented her daughter.

Participating in the creation of Christina’s story was mirror-like. I was frustrated at her not having lots of insight, just as she must be frustrated that her ED team has not supported her better and understood her realities as a single mom. I was frustrated hearing the ongoing struggles she had in her life with her ex-husband. I was mortified how she felt judged by the ED team. I kept trying to “look for the distress” in Christina’s appearance or facial expressions. It dawned on me the depths of the stress we do not see. She told me about that (the crying in the
At that point in time, we didn’t even have eating disorders on our mind. It was more like she’s got some real anxiety around food. [My daughter stopped playing high level sports], she was 117 pounds and that was all 117 pounds of muscle. She needed to grow, right? That was probably one of the hardest. That was a hard part for her. We were referred to a dietician at [organization name]. He was excellent. He was really trying to get her on a program where she was eating regularly. [At] the second visit, we got more into her relationship with food and how it as making...
her feel and that was kind of when he said, “you know, that’s out of my area of expertise. You need to get help in other places.” That led to a referral to somebody at [same organization as dietitian] who then referred me to [outpatient ED clinic]. I had a hard time actually connecting with the [outpatient ED clinic]. I went to the website. I was like, “I don’t know what to do. Where does it say what to do?” [The dietitian said] it was self-referral system. She went through it all in an email to me.

I think that’s kind of where it started to spiral. [Although the ED team] do maintain that the bad relationship with food has gone on for a lot longer than that. Trying to find [my daughter’s] normal in everything has been very, very difficult. [My daughter’s] normal in terms of level of activity, normal for weight. There is no weight (goal) for her. It’s one of the things we’ve struggled [with]. I’ve sat there with [ED therapist] and said, “Can somebody just tell me something?” Nobody has an answer. What weight should she be? They’re like, “We don’t know.” I think I finally just said to [the ED therapist], “Okay, she’s feeding herself. Her weight has come down significantly because she’s not training. So, her muscle mass has come down.”

It’s hard when you don’t have a regular path. [For the] medical part of it, they tried to track her weight and so on and so forth, but there’s not enough data there. I think one of their flags was that her weight from grade nine to grade twelve went down. Not hugely down, because she did weigh more when she [was playing sports]. I think it’s kind of funny because they sit you down, they tell you this diagnosis, you meet with a dietitian who says you’ve got to do mechanical eating. I’m like, “Okay.” Then they give you a piece of paper saying you have to take over your child’s eating 24/7 and then you have to do this, you have to do this. Somebody has to be with them all the time. It was this very shocking, kind of scary list of things you have to do. I looked at it and went, “Her weight is up right now and she’s trying to eat more. We don’t need to do this.” So, we didn’t. We didn’t in the beginning, which totally threw my husband [through] a loop. He’s very much like [his daughter] is, with his own set of anxieties as well. Then you go back (to the ED clinic) after a week and you talk to them. I was like, “Well, we didn’t do this,” because after that meeting, [my daughter] said, “I will try to eat more.”
Her eating disorder basically looked like anxiety over what she’s eaten. She likes food. She likes to bake. She likes to eat and so forth, but the symptoms that we saw were that she would eat dinner with us and have a complete fallout. Crying. “I hate myself. I’m so stupid. Why did I eat that? I’m going to be fat. I’m so obese.” It just was kind of this cycle of, if I eat my one egg for breakfast, my salad for lunch, and my whatever it is I’m eating for dinner, I’m fine. But as soon as I actually eat what I want to eat, or if I snack too much, then there’s fallout.

We spent a lot of time in denial for the first little bit. [The holiday] was terrible for her. We were staying in a [hotel] and she would come into the [hotel] and be just like pinching herself and crying and just like going crazy because there’s so much food and she’s eating it. She’s snacking. So mechanical eating had gone completely off the rails. Her weight was coming down because, a) she wasn’t training anymore, and b), at that point in time, she was really kind of pulling in on what she was eating. Then emotionally, she was a mess over [that] weekend. We came back after that and we all went in (to the ED clinic) as a family and told [my daughter] that we were going to take over control of her meals. We put a very traditional program in place where your parents take over everything. The first dinner was fine. The first breakfast was insane. She said, “This is too much food. I’m not eating this.” The plate went flying and the juice. I got winged by one of our big plates. I have this massive welt on my legs. Stuff went flying everywhere. We had a period of extreme emotion from [my daughter], extreme emotion to do with how she was feeling. A lot of it was about eating, and then body image, and I hate myself, and the scratching. She would lie on the bathroom floor and cry and say how awful her life was.

All of [my daughter’s] emotions and aggressions were all pointed at me. [My husband] works late, so I changed my work schedule so I could be here. I did a slightly reduced schedule. So, I was the main focus of it. Crazy violent. Throwing dishes. Throwing food at me. She’d kick me, hit me, scratch me. We (once had this) huge blow out. It was a Friday night. It was over the food. She would eat it because she knew she should eat it, but then she would lose her shit about eating it. That particular night she was eating off a paper plate. She ate some of it, but she said it was too much and she winged it. It was all over the kitchen counter. Then she gets very angry.
Then she comes after me. It was just this huge explosion. She was kicking. She was screaming. I locked myself in the bathroom because she was all over me. That was really the pattern that we had that she was always all over me. [The ED therapist] said, “You just have to make sure you’re safe.” I was like, “I don’t think I’m safe.” She scratched me or hit me with something on that particular [day] and I was bleeding. My wrist was bleeding. I was fending her off. I shoved her hard. I shoved her to the ground and went into the bathroom and locked the door. And I was devastated. I was devastated that I pushed her. I had to shove her. I had to hurt her. I was angry by that time. You’re angry and you’re frustrated and my goal in that moment was to hurt her enough to get her off me. To get her to snap out of it. Like that’s what you’re thinking, “Oh my God, snap out of this! You’ve got to stop.” And I think, “Oh my God! I didn’t do anything right there. I didn’t get her to calm down. I didn’t do anything right. I shoved her off of me and locked myself in the bathroom and she put her coat on and went out for a walk,” and I stayed in there hyperventilating and crying for a very long time.

I got to go away for a week. My parents were going down [South] for the winter and I went down for a week with them. But, interestingly enough, that week away made me realize how incessant that kind of… you know, constantly in my brain, constantly worrying. I think there as a point in time where [daughter] was texting me, and [husband] was here in the house, and I texted him and said, “You need to deal with this. This is not fair to me to try and deal with this from this far away.” But being away and getting a little bit of respite from [the ED] does make you realize how constant it is.

You put on your armor and you go to battle and then you take your armor off and you cry. Really truly. Because that’s how it works. Unless you’ve been in it, you can’t imagine it. She [doesn’t] remember a lot of those violent times. A few of those times we talked about it afterwards, too. A lot of it is, “I’m so sorry.” [My daughter] has spent a great deal of time telling us how sorry, so sorry she is that we have to go through this. When she gets really worked up, one of the things she does, again at me is, “You can’t handle this. You didn’t sign up for this. You shouldn’t have to deal with this. You can’t handle this.” Yeah, and I literally stand there and go, “I have handled this so far. I’m not showing any signs of not being able to handle it.”
[My husband] doesn’t handle any of this. This is where it was so hard on me because she would be getting heightened and she would be losing her shit and slamming doors and throwing things, and he would be losing his shit. He tried. He did try. He tried to go in and talk to her, it’s just his ability was not there. He’s really tried to help. Often, I would be focused on trying to get her settled down, talk to her, try to do whatever I could to calm her brain down, and meanwhile, [my husband is] elsewhere in the house losing his shit. He would get so mad at me because I’d get done with [my daughter] and I’d walk into the bedroom and he’d be like, “She’s so bad. We’ve got to do something. This is so bad.” I’d be like, “I have no fucking time.” I’ve said this over and over again to him. I’m like, “All my emotional energy goes into her. I cannot deal with you.” I don’t want to be disloyal. I don’t want to say he’s not doing anything. I don’t want to say he hasn’t tried, but sometimes he just doesn’t get it. He gives me credit. He says, “It’s all on you.” I was like, “Yeah, but I don’t want it to be on me.” He said, “You handle it so much better, and she talks to you and blah blah blah blah blah.” I’m like, “I don’t want to be the only person in this.” There was actually a time that it got bad enough I said, “You know what? You just leave and I will deal with it.” It’s hard ‘cause it’s not like I would actually want to go through this whole thing on my own, but it’s hard to fathom how you would even share it. I don’t even know what it looks like to share the burden.

I spend a lot of time assuring [my husband] that she’s fine. Then I feel like, if she’s not fine, or if this rolls backwards, then it’s my fault. When it comes to the treatment, and when you’re in charge of the treatment, when it doesn’t go well, you’re responsible. You feel responsible, I feel very responsible right now, because [my daughter’s] feeding of herself isn’t going as well. You question whether you’re doing it right. Every time [my daughter] says that’s too much, you question whether that’s too much, you know? Everything that you do you start to question. You lose your confidence, which is big thing. You lose your confidence right off the bat. Like, “Shit, I did it wrong.” I think when you’re in it, you’re just in it. You do what needs to be done, and you just keep going and you do it one day at a time, and you soldier on. It’s like, “Okay, after this day, then we’re on to the next day, then the next day.” Then sometimes it works and other times it builds up. I mean I’ve gone to [the ED therapist] a complete mess because I
just lost my ability to hold it all together. You’re like, “I’ve got it all together and it’s good and I’m keeping it together,” and then it all falls apart. Some of my falling apart stuff does have to do with [my husband]. It’s very hard to be on all the time for your kid, and then try to be on for your spouse as well.

I wanted FBT to just say, “You know what? We’re going to give this job to you mom. This is what dad gets to do.” Dad gets to do one meal and that’s his challenge. You’re buying into a program anyway, but I would have loved to have had more information up front about what I’m going to run into. You may run into people who do this, or you may run into people who do this. I don’t even know what this and this are still even. I couldn’t even tell you, other than FBT, what else there really is out there. There are times when you want a map. You want an overview. And I’m quite sure that that goes against everything that the program kind of is supposed to be, but you want somebody to say, “Okay, this is your roadmap. You’ve got to do this. This may take forever. You could be feeding them for a year, two years, whatever, but that’s what you’re going to do first and then you’re going to do this.” You’re so overwhelmed by stuff. In the beginning you listen to what they say and then you read. You’re on the internet all the time. I was on every chat site and so I was going, “Okay, I need more information.” That was kind of my constant feeling. It still is actually. I need more information. I need to know more about what I’m supposed to do here. Even in the beginning because I mentioned that we get this list and we’re supposed to do these on the 24/7 thing.

You get so focused on food prepping and so forth. It’s constantly like, okay, what’s, what’s the next meal? Sometimes I would like to only have to worry about myself sometimes. I think that that’s the hard part, I think in the beginning, you spend a lot of time going, “Well, I know my child, I know what she needs, we’re entwined.” As it goes on, that confidence erodes. It’s not that I don’t know my child, it’s I no longer know what’s best for my child. I want somebody with me all the time saying, “That was right. You could do that differently. That was really supportive. That’s the eating disorder.” Because [my daughter] thinks she knows what’s best for her, [my husband] thinks he knows what’s best for her, and I used to know what’s best, and now I’m like I don’t fucking know what is. Yet, I’m the one who’s responsible for actually
making the decisions. I say, “Trust me, I’ve got this,” or “I’m in charge of this and I’m not sharing everything with you (my husband).” Then it becomes 100% of my responsibility, her success, or failure is 100% on me. I mean, her success and failure are 100% on me, I’m quite sure [my husband] thinks that too.

My husband always says that I’m doing my best. I don’t think I’ve ever said that about myself. In my mind saying ‘the best that I can do’ means that what I’m giving you now is the most you’re going to get from me, but that’s not necessarily the best that I can do. Maybe I can give you more. Maybe my ability to support you will get better or maybe it’ll change or maybe I’ll find something different and maybe we’ll figure out a way to talk. I mean I am doing my best. I am working hard at it, but I always think that there’s always more that I can do. I’m always interested in knowing if there was more than I can do.

There’s been so much intensity, and it goes up and down. Like there’s been incredible intensity and then there’s been kind of, a little bit of intensity, incredible intensity, a little less intensity. It’s been so much all the time that I think you become a little bit numb to how much it’s taking out of you. There would be days where I just would get up in the morning and know I couldn’t handle it. Unfortunately, the hard part about that was because [my husband] wasn’t ever really able to just step right in, there were just days that I would say, “Oh, I did it all wrong.” [My daughter] would start to kick up a fuss about something and I’m like, “Fine. I don’t care. Don’t eat it.” I am not a controlling person. For me to take over somebody else’s control is a big leap, personally. That is not my type of parenting. [My daughter] is a kid that has never needed a lot of parenting. I had friends whose children were not allowed to eat at other people’s houses ‘cause [they] didn’t know what was in the food. I was like, “But my child was the one ended up with the eating disorder. How did that happen?” You think back. I’m like, “What did I do wrong? How did I miss teaching her about food?” It’s anxiety causing. It’s emotional. It’s tough at times. There are times that I get overwhelmed with oh my God, why me? Why us? Oh my God, what did I do wrong? There are times that I get overwhelmed with that for sure, but I also don’t look at it as doom and gloom. I have absolutely no doubt that [my daughter] will come through on the other end and be absolutely well-functioning.
It’s very isolating, the process. You don’t have a lot of people to confide in, so I found it very isolating. I think I opened up to my sister in the summertime, but even in the summer we were dealing with the emotional part of [my daughter]. The part of it where we took over the meals and everything just went to hell. That part I didn’t have anybody to share that part with. There was nobody that was close enough to the situation that I could even talk to about it. I think all along it’s just been an isolating process. You don’t have a lot of people you can just chat with about it or that even know where you’re coming from. I really do rely on [ED therapist] a lot. [ED therapist], she’s awesome. Sometimes it just took writing an email to [ED therapist] to bring it back around so I’m like, “Okay. Okay, I’m okay now.” Sometimes it took me sitting down with [ED therapist] and just working through stuff. I spent time with [ED therapist] where we did, I did, chair work with [ED therapist] where you’re trying to kind a get to the bottom of, you know, the back and forth.

I’m not from [this city], so I don’t have a really strong friend group here. Also, this past year, I have avoided stuff. I’ve avoided social outings or events or whatever that are a little out of my comfort zone because I just don’t have it in me to be out of my comfort zone right now. I’ve avoided some work stuff that I really should have been a part of but it’s a stressor (for me), and it’s pressure. It requires me to be at the top of my game and talk to people and be confident and so on. And I avoided it. I kicked myself afterwards. It was really mad, but I avoided it simply because I thought it takes emotional energy I don’t have.

I think to myself, without the eating disorder, maybe I’d have taken up a hobby? [I’d] go to the gym more. But I don’t usually dwell too much on that. I just kind of plan for future hobbies, right? I have [art] in my future. I literally have not looked to the end of this month. When you’re so focused on getting your child to the start line or the finish line or the line, getting them to a place that they’re healthy, you don’t have time to think about [the future]. I haven’t had time to think about me. I’m like, okay, I’m committed to being here for this. I desperately would like to find a different job. It’s time for me to find a new career. I wouldn’t mind something different. I need to figure out something new for a career, either a new related job or a new career. I haven’t decided. I can’t even begin to look at that until [my daughter] is well settled.
You just don’t have the emotional energy. Finding a new career, looking for a new job takes emotional energy. And I don’t have enough emotional energy to do anything else right now other than support [my daughter]. For [my husband] and I? Good Lord. If we, if we survive this, we’ll need to do all that relationship repair stuff. We will absolutely 100% need a little bit of work with that because the two of us, I think both of us, me dealing with [my daughter] and him dealing with his own anxieties, neither one of us has time for each other. We have moments where we’re okay, but on the whole, we haven’t had enough time to support each other, and we will need to, we will need to fix it. Right now, we’re both just trying to get through.

**Listening to Cara.** Cara was easy to chat with, and getting into her story was easy, but her story was complex due to her daughter’s diagnosis and onset being quite atypical. Cara’s daughter was involved in high-level sports, and thus had quite a muscular body and, since an early age, had specific diets to follow in order to perform her best in the sport. While Cara was talking about the challenges of trying to find her daughter’s normal, as a struggle for her and the ED team, I couldn’t help but feel lost and uncertain with her. As a clinician who had some individuals involved in high-level sports, I recall always taking an “informed guess” about what was the normal for those individuals. For those mothers, an informed guess can’t be the most comforting thing to hear.

When Cara spoke about wanting some sort of a road map, a familiar feeling overcame me. That wanting-to-know feeling. That needing to know that there is some loose guide to follow through this uncertain process. As a clinician I remember those feelings of being “off the roadmap” and families not meeting the checkpoints outlined in manuals and feeling lost and uncertain myself. I hated that feeling. Even as I do this research, the narrative has no road map *per se* that lets me know that I’m on the “right” track. This is an unsettling, uncomfortable
feeling. I try to place myself in Cara’s shoes of trying to support an ill child while feeling uncertain and unsettled, coupled with the feeling of self-blame. If Cara does not do enough for her daughter, she is the lone person in the caregiving role for her child. Essentially, there is no road map provided, but there is a sense that she is to blame if things don’t go well. That feeling is excruciating.

When I think of Cara, the image of Miller’s (1943) “We can do it!” poster from World War II comes to mind. When I hear Cara talk about managing not only the incessant nattering of body image comments and the violence from her daughter, but also her husband’s relentless worrying over not doing the treatment exactly as outlined, I am just dumbfounded by her ability to continue to soldier on. Especially without direction, and on her own. Cara spoke about having a great, supportive ED team, but I envision them not in the trenches with her but navigating from the control towers. Just as Miller’s (1943) poster was to boost female morale in the workplace, Cara does elicit a feeling of power within me. I feel, through hearing her speak, that she really can do it, despite her exhaustion, the violence she’s endured, and the uncertainty. I am simply amazed at her desire to learn more, and to practice the skills learned in therapy in order to manage her daughters’ tough emotions.

When Cara and I met for the second interview, she admitted to not being in her best frame of mind. She had had a rough night with her daughter and felt that her daughter’s recovery was sliding backwards. Cara talked about the verbal and physical violence. As I sat in her home, I noticed how little space there was for her to escape or maneuver away from her daughter when plates or other large objects went airborne. It dawned on me that her ability to maintain this “I
can do it” attitude must take a substantial effort that may go unnoticed in the therapy room. I also began to wonder if this “I can do it” mentality is a positive mindset, full of energy and a desire to conquer this illness, or if it is more of a “I can do it…. because I have no choice and my husband can’t do it.” I feel the urge to disclose when I hear Cara’s story and her talking about her shame in having to shove her daughter off of her and feeling like she “didn’t do anything right” in a violent moment. A true confession: I don’t think I would be able to do what she has done. I think I might have given up.

In fact, while Cara wonders what she has done wrong as a parent, I have a feeling of resentment towards her daughter. Cara has literally adjusted her whole life to give her daughter opportunities in life, to essentially get her back to health, and in return she’s met with violence. I’m perplexed by my reaction as I know that this is the ED taking over her daughter and causing her distress. I know it’s not her daughter’s fault when she acts this way. But when I hear Cara’s story I am struck by how much pressure and responsibility she has put on herself, and how very little on her almost-adult daughter. I am enraged for Cara (not that she needs my outrage). I’m enraged that she is feeling alone in this process, enraged that her husband cannot support her more. I am enraged that she has had to adjust her life and her parenting style, and I’m enraged that she is not as enraged as I am. I’m enraged at the violence. As a social worker who obviously does not condone violence of any sort, and struggles to write this sentence, I think Cara did everything right in that violent moment, and it makes my stomach churn to hear that she doubts and criticizes herself for her natural reaction to an unnatural situation.
To reveal that this violence is happening in her home is an incredibly vulnerable thing for Cara to vocalize. I feel that in the ED world, we do not talk about this violence enough, because of the shame that Cara mentioned, or the fear of being judged. I have heard of parents having to be forceful when their child is violent, and I’ll admit that my clinical training encourages me to immediately ask, “Do I have to call F&CS?” But, when I hear Cara speak in such detail, I have no doubt that she did exactly what she had to do in that moment. Perhaps others may judge the violence, but hopefully upon hearing her narrative they gain a picture of what goes on inside Cara’s mind when she beats herself up over her own reactions.

Being a co-creator in Cara’s story really brought up a smorgasbord of other emotions and reactions within me. First, I am cognizant that Cara’s daughter’s being a high-level athlete is not typical, and thus I want to protect her confidentiality as much as possible. In addition to that, I want to portray Cara in a way that shows how incredibly tenacious she is. I want to protect Cara, especially when she admits to the violence. I almost want to keep that out of this narrative in order to protect her and paint her purely as the determined woman she is. However, she herself admits to struggling, to questioning herself, to feeling blame, and to “doing everything wrong.” I have to co-construct her story with warts and all but want her strength and her persistence to be at the forefront of the account. She’s adjusted her work life, she’s taken on the burden of her husband’s emotional needs, her body has been attacked, her mind is in turmoil trying to figure out if what she’s done is “right,” and she can only remain speculative about her future. And yet, despite the losses, in my eyes she shows no signs of giving up supporting her daughter. She can
do it. She will do it. Her story leaves me with a contradictory feeling of being both energized and exhausted.

**Cordelia**

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[My younger daughter] I speak more about, because [my older daughter who also had an ED] is doing so well. [My younger daughter], she’s got a very loud eating disorder. And she’s not weight restored yet. We’re still in phase one of family-based treatment, we’re getting closer, but it’s still, tossing food, spitting food out. I would get her breakfast ready and then have to sit right at the table with her while she ate it. Partly to supervise it, but more importantly to support her through it. Because it was so hard for her to take a bite and swallow it, so I would be there for that. I almost feel like I am out of my body at times, literally, that I’m sitting there looking at somebody who I don’t know with [my younger daughter] … it is like I don’t even know who she is, where she came from, how she became the person that she is today. Because it could be very different in the next hour or the next day. It’s just all over the place so much. I do sit there, and I don’t recognize myself or [my younger daughter]. It’s almost like I’m in a dream watching something in that dream that can’t be real, but it is. And it really tells a tale of what I was living through at home and that she can be like, “Ahh!” Like she’s rocking, and pulling on her hair, and screaming “the pudding you made me eat, the pudding.” Is this for real, is that my kid? We had
to pull over ‘cause she was overreacting so much about the pudding she had to eat before she went to dance. And it was at that moment I’m like ... I didn’t even know who I was. It was so weird.

I was so mentally burnt out myself that I just put up this little blocker around me. Just to keep it from affecting me. Or I might have been rocking there and crying beside her. Like I was just tired, I was so tired, and I just was, my mind was always on [both my daughters] I wasn’t genuinely engaging with other people. I was short with them. I was very absorbed in my own problems. We started a family-based therapy or treatment in [the fall]. I managed to try and do my best until [winter] and then I just couldn’t do it all. [My younger daughter] would go to school at 7:30, I was starting work at 7:30 a lot of those days, because we would have appointments and I was still trying to fit my 32 1/2 hours a week in at work. And so then I would get her from school, because she couldn’t be trusted actually to do the lunch and two snacks, so I would supervise everything at that point but lunch and morning snack. Then I would get her at 3:00pm when school was done and then she would either have appointments or dance, but in the meantime have to feed, snack, supper, snack again. And, you know, each snack was supposed to be twenty minutes, but it was like 45 minutes and the meals were, some days they just didn’t finish, you had to stop the fight, but there was just no end, you know? That’s how it was until I went off work, it just burned me out. It’s tiring, it’s frustrating, you get pissed off, become resentful.

Before I went off work, I was resenting my kid, the eating disorder, my husband. I was the most resentful person. [My husband], he might come home, or we’d be talking, and he’d complain about his day. And I’d be like, “Okay. You’re staying in a hotel, you’re not cooking any meals, you’re sleeping in a bed by yourself. You go to work and that’s it.” And I was feeling like he didn’t get what I was doing in a day, which literally would start at 5:45 in the morning and go ‘til 10:30 at night. I just felt like he wasn’t in tune with what I was doing. Or wasn’t being supportive enough. I didn’t want recognition so much as just some support. Someone to say, “I know it must be hard.” And I didn’t get that from him. So, I would become very resentful and think if I could just be away and just have my work to deal with, life would be grand. I felt like
his job was the priority and I’d heard of dads taking leaves to stay home and caregive. I wish for only a smidgen of that at times. Whereas he could just today say, “Oh, I’m going to be away next week.” I’ve been planning for my week away (a trip with girlfriends) for months now. And I’m still feeling anxious about it. Thinking if he could just help around the house in a very productive way, then he was at least contributing a bit. He’s the first to say there’s nobody that has a relationship with both girls other than me, we have the strongest relationship. It’s different for him. He was always the fun guy. But when it came to the emotional side of the girls, he doesn’t get it the same way. And he’ll admit that. So that always came to me, I guess.

I started questioning my faith, why us? Why two kids (with EDs)? I kind of became a little pissed off at life, but I don’t know anyone with two kids that have it, right? I also, it forced me to become very isolated, from anything social, because so many hours a day you’re caring for your kid. If I was invited for lunch or dinner, I couldn’t go. And I still lots of times can’t. It becomes that way, that your whole focus is on that kid and you can’t do anything during that time that you’re with that child. So many feelings, strong, feelings that I wasn’t used to either, like I was never an angry person or judgmental. I became very judgmental about my friends or my sister, like, “Their kids are normal, why? It’s got to be something, I need to find it.” It’s very isolating, not only isolates your child, I think, from their peers and life, but also their family. I know that at one point [my husband] and I met with [an ED therapist] and we were just expressing a bit of conflict in our marriage, and our beliefs and what was best for [our youngest daughter]. I think at that point she noted that things were very stressful for us, maybe as a family as a whole, not specifically for me. And I remember her saying like, we don’t want eating disorders causing divorces.

I’ve never felt anxiety before, life was pretty easy for me. I didn’t know it until I was forced to sit down and feel it. My whole body was just vibrating on the inside and I didn’t even know it. The doctor, the nurse practitioner and [my own therapist] said, “You need to take some time off,” so at first, I said, “Okay, four weeks, I’ll be back after Christmas.” And then the doctor said, “Four weeks won’t do anything for you, we’ll write for six and then reassess.” I went back and they wanted to write another twelve weeks off, make it a full sixteen.
[My own therapist] helped me recognize that I kind of took caregiver fatigue to a whole new level. It was mental, it was physical, and I didn’t realize how tired I was until I stopped work. There was like a real physical side of health to me, aside from the fatigue and the exhaustion, there were a few things in my blood that was out of whack that they could only really connect to the stress and the pressures that I was placing on myself. My sugars were high, physically, I had chronic fatigue. The first week off I slept the whole week away. An airplane could have crashed in our house, I wouldn’t have cared, I was so tired. When I went off work and was able be there for [my younger daughter] and prepare meals, and my mental state was all about [my younger daughter], the weight started going up rapidly. Prior to that, there might be two ounces up, four ounces down, four up, it just was not going anywhere, right?

Once I stopped work, started taking care of myself better, my counselor helped me to see that what I was feeling and experiencing was grief. I really am grieving the change in the relationships with both girls, the sense of loss of things they’re not experiencing in life. The relationship [my husband] and I had has shifted a bit. I grieve [the loss of] my freedom, that I just can’t hop in the car. My youngest is turning 18 and I’m still taking care of her like a toddler. I had thought that by this point in my life my kids would be taking care of themselves. And I’ve always thought of being on a board of directors, or something like just giving back to the community somehow. And I haven’t been able to do that. So, there’s other parts that don’t even exist. Like hopes and dreams of my own that have been put on hold while this is happening. We’ve worked a lot on just acknowledging that feeling at the time. Maybe not doing anything about it, but just letting it sit, and then go, “Okay” and moving on. It’s just an acknowledgement and recognizing that I am grieving a lot of things for my girls, for myself, for our household. And then with that, there’s just such a sense of helplessness. As a mom, what can I do to help her? I think moms, me in particular, I feel a ton of guilt that this happened to them. I think it just goes to that protectiveness, you just want to protect your kid, you want what’s best for them. And when it doesn’t work out that way, you just beat yourself up over it. Blame has to get placed somewhere, so moms put it on their own shoulders.
[Family-based therapy] is working for us, but it’s so much teaching the parents, especially in the early days, how to respond to their kid and how to feed their kid. I don’t think the family unit or the individuals within that family really get looked at. I always sought out my own counseling. I wouldn’t say that a real strong point of family-based treatment is the looking at mom and how that person is doing. There’s a lot of really solid strategies to help. Like when I would go and say, here’s what’s happening. Oh my gosh, I don’t know if I can get through another day of this, that’s where the strength is in family-based treatment… it offers you a lot of suggestions, a lot of alternatives and a lot of clear direction. We just have to trust that the professionals know what they’re doing and how to do it and that it will work. I’ve read so much and there’s a good book that I read. I did so much research of my own on it. There are some family groups, like Facebook groups and stuff, that have been recommended to me that I’ve checked out. And then a couple of books have been recommended, so I’ve read them cover to cover. Just to gain as much knowledge as I can about family-based treatment.

The research and the therapist will tell us that family-based treatment is the best. [My younger daughter] is almost 18 though, so she’s at the hard age. I can see family-based treatment being awesome for younger kids, [but] when someone’s almost eighteen you kind of can butt heads with your kid when you’re forcing them to eat, right? We can’t even compare to the full-time staff base and the programs, and the clinicians, and everything that’s at [residential treatment]. And I think [the ED therapist at local clinic] says it’s basically like sending home a terminally ill child and saying, “Look after this kid” when it’s family-based treatment. So, I do the best I can with what we have and what we’re given to work with. So much of it is about refeeding, but I know [my older daughter] was refeeding [at residential treatment], it took two weeks [there]. We’ve been working on it since [the fall] and [my younger daughter] is still not weight restored.

I certainly gained like 10 pounds with the refeeding process easily. We’ve always eaten very healthily… suddenly three meals, three snacks, and I’ve never had three snacks and so I was snacking more often. And a lot of the foods that you’re feeding your kid are more carby or more fatty foods. She gains weight, I gained weight. Like sour cream, I might’ve bought the 5% my
whole life and now we buy the 14% because we’re looking for those higher-calorie items to feed [my younger daughter]. When you’re in your upper forties it can become a little not so great. And even like a walk, right? We can go for walks, but they need to be mindful, and they include the dog, we’re not 5K hike or anything. I was going to the indoor track nearly every day for 45 minutes to an hour. It was awesome. Like, just to zone out, put some earbuds in and get a walk in, you know?

It does take a real planner, I think, to be able to manage a child with an eating disorder. Because even when you’re around, you’re always planning. Planning appointments, planning meals, planning snacks. It becomes you’re almost planning their social activities. She can’t just hop in the car and drive off to a friend’s. You have to work around meals or ensure that it’s a mom’s friend who knows that will keep an eye on her. You always have to be just one step ahead and be ready for what might come. And that takes a lot and [my husband] just doesn’t have that skill, I guess. I just don’t want her to have that weight loss again when I’m away (on a vacation with girlfriends). I’m always vigilant and always planning for the next snack or the next meal, [my husband] doesn’t think that way.

I question the longevity of family-based treatment, like in terms of [my younger daughter] learning the skills to continue on her life with the coping skills and body image and all that stuff still, and like I said, we’re only in phase one. Phase two, phase three will start looking more at those things. Like the underlying things like [my husband] says, we really need to ensure that [my younger daughter] is equipped with a lot of good coping skills to carry on in life. And I haven’t seen that yet in the family-based treatment model.

It’s such a struggle with knowing what’s best. I will do my best with what I’m given, to make [my younger daughter] well, and hope that’s enough. But I know that there’s a plan B (residential treatment) if needed. I do think that I placed [an extra expectation] on myself. I did a lot of my schooling with kids with behavioral challenges, so I always put an extra set of expectations on me, on if my children were misbehaving, how would that reflect on me as a team member at my place of employment. I never said it, but it was always a thought in my mind that my kids should be well behaved.
I got a lot of sympathy from people at work and friends and the community when I took the leave. And I don’t like being the person that people sympathize with. I don’t want people feeling sorry for me and I would get that feeling from people. I do still feel judgment from some people. I think it’s their misunderstanding or lack of knowledge around eating disorders. There’s still a bit of secrecy I guess around [my younger daughter] and what’s been happening with her. A lot of our extended family doesn’t know, but they know about [my older daughter]. I’ve worked a lot through that too, around some embarrassment of my own in having two kids that have anorexia and feeling very judged. I worry, I’m very internalized that way, and feel some shame. I’ve worked a lot on those feelings of shame. My worry is that I would burnout again like I was. Just having an awareness of where I’m at, and that hopefully that doesn’t happen again. But if it does, I know there are other options. I could take more time off work through my work, or there’s an unemployment leave that some moms will take, a caregiver short-term leave or something like that. Hopefully we don’t have to go there. My friends and people I work with, they all said I hide it very well. Like you were like superhuman super mom doing everything and you know, you don’t really have a choice. I think that the friend piece has gotten a lot smaller. Just because I haven’t been able to interact and be with friends like I used to. And haven’t been a great friend to others during this last while either.

I hope [my husband] and I are doing some traveling. That’s really how I see it without the eating disorders in our life. It’s been a long time since the four of us have sat down and just had a normal supper that does not have any food related issues attached to it. I’d love to look forward to that day when Christmas dinner is just that. And we haven’t [sat down together at dinner] for a long time. Or if we have, it’s not been pleasant. I’ve worked really hard on just being here now because I can drive myself nuts worrying about the future. The same way looking into the past because I just can beat myself up pretty good over the fact that both girls have eating disorders, and, as their mom, that shouldn’t be.

I’ve become a much better listener [and] more easy going. I’ve learned how to take care of myself once and for all. I’ve learned that I want to be able to give back to others experiencing what we’ve experienced. I share my feelings more openly now, because I would just kind of hold
everything in. I’ve learned that my marriage is a little more fragile than I thought it was. [My husband] and I, our freedom to just do what we want to do has changed. We try and make a point of coming together every day just to check in with each other. But that can be hard to do on a lot of days where I’m just tired. Whereas we might have that talk or some intimacy before bed, now it’s just like zonk out. There is great hope, we talk a lot about when both kids are gone, it’s just the two of us left in the house. And we’ve worked really hard our whole lives to make sure that we still know who each other is, and that we are still in tune with each other. But that really has changed the last six months. Prior to the eating disorders, we would always take little mini trips away. [We] always made sure that we were still a couple outside of the kids. We just don’t have that opportunity anymore. I have a really close great relationship with my mom, and my hope has been that I would have that relationship with my girls. I know it won’t be tomorrow, but that’s kind of where it’s gone, from just hatred towards life and God for doing this to us to “okay, it is what it is.” And just finding those moments to laugh at is, yeah, is the best thing for me, just to laugh it out.

**Listening to Cordelia.** Cordelia was the first woman I interviewed for this research. She has two daughters, one who is in remission and another who is still actively in treatment. I remember receiving Cordelia’s email, where she told me she had two daughters with anorexia, and right away my brain went to, “What is going on in this family to have two daughters with an ED?” I hate having that thought, and I hate even more admitting it. I know the genetic links and that it is not actually unheard-of for two children to have eating disorders in a family, yet somehow my own automatic thought was that there was a genetic deficit in this family. When I met Cordelia, I was ashamed that that thought had crossed my mind. This reminds me very much of being a clinician, reading an intake note, and already formulating what I thought of the family before even meeting them.
Cordelia told me her story clearly. She began with how her father passed away, then her older daughter went to an adult residential treatment centre. Three months after her older daughter was discharged from the treatment facility, her younger daughter was diagnosed with the same eating disorder and began family-based therapy. When Cordelia spoke of her own diminished well-being while caring for her younger daughter and having to take a leave of absence from work, I couldn’t help but wonder if my entire interpretation of her and her story would have been vastly different had I met her earlier, before she had taken time off work. How would I have conceptualized her story if I had met her when she was having those “out of body, dream-like” experiences, when she was full of resentment? Perhaps she should not have even responded to the research opportunity; she may have been too taxed emotionally, physically, and logistically to meet with me.

Cordelia’s job is similar to social work, so when we spoke at times it seemed like we were talking professional to professional. She really is a professional mom-to-children-with-an-ED, something beyond my own experience and training. In fact, when Cordelia mentioned that she puts her trust in professionals, I couldn’t help but notice a lump in my throat. Through all my own education, training, and research, I still don’t completely trust my own intuition. It became clear to me as Cordelia spoke, and was able to connect with her body and her needs, and to examine herself and think critically of what “she can do with what she has,” it dawned on me that I do not think I ever looked at mothers and thought of what they could do with what they had, but rather I looked at what they should do, regardless of what they had. They needed to get creative (spend more energy being creative) to fill the deficits they had.
Cordelia’s questioning of the treatment for her younger daughter made me wonder if she was trusting the professionals and had the space to ask these questions to her clinician, or if these were thoughts she asks herself, rarely spoken out loud. I raise this point because I too have similar questions about the treatment and its longevity. Hearing Cordelia’s story made me wonder if there were spaces for these women who were implementing the treatment to come and discuss their apprehensions concerning the treatment. The mental work of planning, thinking, and reading about treatments, I feel, is often not expressed or brought to light. It is only through these interviews that I have received a small sense of what it is like in the mind of Cordelia, and other women, living with a child with an ED. Cordelia’s story is not simply waking up, making meals, and supervising. It is researching and planning, learning, implementing new things learned. It is adjusting the things that have not worked, it is sacrificing, and it is a hell of a lot of emotional work.

When I look at the initial email in which Cordelia stated that she had two daughters with an ED, and now reflect on our last session, it is quite the journey. I went from total judgement and concern, to complete admiration and hopefulness. Participating in the co-construction of Cordelia’s story was a learning endeavour for me. Not all of these ED stories are doom and gloom. Of course, these stories are hard and rife with challenges. Even stories such as Cordelia’s, which, on the surface, sound like living nightmares, still have hope and growth within them. While Cordelia admitted to not thinking too far into the future for her own sanity, she did have some hopes. These aren’t grand hopes and dreams, but more typical hopes and dreams that she appreciates more now having gone through this experience. She said that while this ED shook
her to her core and affected her on a mental and cellular level, she can appreciate how this experience has contributed to her growth as a person. I entered Cordelia’s story with a feeling of despair and prepared myself for a woman who was at her wits’ end and full of anger, but instead am leaving Cordelia’s story with a sense of hopefulness and delightful surprise at the way she has told me her story. I leave her story with a renewed optimism for women going through this experience.

_Adrienne_

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I think she had some issues at nine years old. We tackled it. And then a year and a half later she started restricting again. I actually think she was probably really diagnosed at nine. I don’t know what happened, but it was because she just listened to me. [The pediatrician] said, you eat what your mother says to eat. She ate and then that was it. Second time around was not so easy. [It was] devastating. All we saw was death. I could not see recovery. I could not see a better life. I thought she’d die. And no one told us, nobody told us, for a month really, what the diagnosis was. You know in your head what it is. But no one said the effing words.
So, three and a half weeks total (of hospital admissions). Two and a half at [an inpatient hospital ED unit]. I had to beg [the ED unit] to tell me what the diagnosis was. I had to come to the family meeting and say, can you give me a proper diagnosis please? And why haven’t you spoken with me as a parent? So that was our introduction to ED. Nobody sat down and had a proper education session for us. Nobody introduced us to what all the terms meant. They hand you papers to read, but no one speaks to you. [A book on EDs was] thrown at us. I can’t explain it any other way. It wasn’t, “Here, this book might be really good and if you have any questions, come and talk to me.” It was, “Here’s the book, family meeting: Monday 11:00. You have to be there; you have to rearrange your whole schedule and be there.” I’m in this foreign world and no one is telling me what’s up or down. No one told us anything. Nobody said, “You are really the main therapist.” I’m sorry, FBT means fucking by the seat of your pants because no one tells you. A mother, parents, know best? That is fucking bullshit. If we knew how to get our kids to eat, don’t you think we would have done it by now?

My child was not violent until after discharge. She still had to gain another 20 pounds when she got home. My child was compliant (in the hospital), wanted to be the best eater, in hospital. So, she ate well. She had, there was one roommate for a few days who was doing ED tricks… hiding her food and her things in napkins and stuff like that. And she (my daughter) would say, “I’m not bad like her. You know mom, I’m a good girl, I eat my food.” So, she ate really well. So, I thought it would be exactly the same at home. Nobody prepared us. Nobody said, “This might occur. Violence might occur.” Nobody prepared us for that. She was angry at me, and she wouldn’t eat, and she’d glare at me and yell at me and throw things. I’m very angry at every single person that we met who never said, “Let’s think about the worst and have you prepared, rather than suffer in silence and feel shame and not discuss it with us.”

My daughter called 911 on the first day home from hospital. It’s a Monday night, we’re supposed to have snacks, she wouldn’t finish her snack. I said, “Well, you’re going to go into your room until your dad gets home with your medication and dad and I will sit with you and you’ll have your snack.” I picked her up, put her on her bed (and then) she phoned 911 and said I assaulted her. I was physical with her. I didn’t know she did this and all of a sudden, why [are]
the police calling me? I go, “What?” It is real and normal and common and expected. And nobody voiced that for us. I felt ashamed having this in my home and saying, I can’t even tell the doctor about this because I’m so ashamed. No one told me (what to do) if she called the police. I had to ask for that from [Community based ED therapist], our therapist. And she was very good about saying, “Adrienne, if this happens, you give them my card, and my phone numbers.”

I said, “Why don’t you tell me about the violence? I thought I wasn’t allowed to speak. I thought it was unspeakable, because of the shame I was feeling in my home, because no one’s ever brought it up with me.” “Oh, we don’t want to scare you. We don’t know how much to tell you because we don’t want to scare you.” I said, “You need to give us everything. As painful as it is, you need to give us everything and you haven’t done it. Why aren’t you telling people?” “We struggle with what we tell people because we don’t want to scare them.” Are you fucking kidding me? Parents are already scared of their kids with an eating disorder. So, are clinicians scared to tell moms what’s going on? I don’t know if they’re scared, but they don’t want us to get upset and worry. My kid’s going to die. I think they sugar-coat things. I think everybody does. I wonder, and I’ve been told by our therapist, our social worker, that “because [of your profession], I think I treated you differently and thought you knew everything.” I have knowledge, I have connections. I know, and I still did not know. And if I struggled, someone who doesn’t even know what a carb or protein or fat is… come on.

Nobody explicitly said, “Let’s pretend you know nothing and go through everything, to make sure we have no gaps in knowledge.” That is where I feel there’s a huge disconnect, and I’m trying to ask our [ED team] and begging them, “Can you please help with the education? I can be your go to.” You know your kid can recover and yes, there might be violence, but we can help you through this, because that wasn’t told to me and I am so bitter about that. I had to go to the Internet. My team couldn’t help me. And nobody said, “Does your daughter do this? Yes or no? Does she hide things in her room? Does she purge? Does she?” I did not know any of that, I was so naive. Nobody told me that. I really believe it needs to be treated like any other medical illness.
I’m very, very angry and I think it needs to be medicalized. I think there needs to be a proper education session for the parents. You bring the kid for an hour, and they get weighed and measured and they go home or go to school. Then you bring the parents in for two hours and you ask them, and you quiz them: What are her ED tricks? Have you noticed X, Y, Z? ‘Cause I didn’t know. I needed “Do A, then do B, then do C. And if that doesn’t work, do 1, then do 2, then do 3.” I really needed a proper road map, a proper protocol. For me I needed a black and white thinking A, then B, then C and if that doesn’t work, C, D, E, F. That’s what I needed, and nobody gave it to me.

Not one person tells you, “You are really in charge, and I’m going to help you over here on the side. What is she eating currently? I want you to add five tablespoons of oil to that.” To support a mother dealing with this [the ED team] should have done this work and gone through the grocery stores and figured out which had the highest whatever, not me. You should have figured out which brands of bread have 10 more calories per slice, not me. That did not happen. I did that for them and gave them the effing list. And I think they get offended, their sensibilities get a bit offended when I come in then, and say, you guys need to do a better job. You’re asking me to be open with my feelings when I come in for my appointments. Why can’t you be? [The community-based ED therapist] is wonderful. I must say I’m happy with her and she listens to me. And not just listens, she hears it. It’s not just [falling on] deaf ears, she gets it. [ED therapist] is very, very open.

I still look at my husband, to be honest, with disgust. That he can’t see what I’ve done and what the outcome is. I am very angry about that. [It took a toll on my] intimate relationships and [my] other children. I think it was very hard on the older two kids and I had nothing to give them, and for that I’m very guilty. [My other child] got accepted to university, a couple of scholarships and I’m like, “Wow, where did the time go? I feel badly. I feel like I’ve missed your high school, and I’ve missed who you are. I didn’t know who you were.”

It brings up the shit in your marriage, and then it makes it shittier. I don’t know how you get passed that. Maybe some people are really into getting therapy and support, but I am so angry and so resentful that I don’t think there’s much there. I had been truly unsupported by a very
weak man and I am very angry and very resentful. Period. I am very angry, very resentful, very angry, very resentful. [My husband] kept reading [that] everybody dies from ED. So, he gave up. He said, “If she wants to die, let her die.” And I said, “No, we need to have hope and I need you to support me in this hope.” And I remember screaming at him those kinds of things. “You need to support me in the hope and recovery. And please read the things on F.E.A.S.T (an ED website for parents) and the recovery stories and how much better kids are doing and they’re sicker than my kid.” He couldn’t and he wouldn’t. Someone put up a thread (online), “How do you save your marriage?” and it got me so angry. You know, “make sure the bedroom is ED free.” Fuck that, I have three kids. The only place is the bedroom to talk about it (ED). And I’m not going out for dinner with my husband because I’m feeding the other kids’ dinner. Other people can say “I need time for me, and I need to be me and I’m going to go and have sex with my husband and go out for dinner. Nope. Don’t touch me. Don’t look at me. You’re not helping me. I am angry. I’m resentful. You don’t understand it the way I do. You won’t read what I’m reading. It was all me. And I will take credit for that and I deserve to take credit for that. The best compliment he ever gave me was about a year ago, he says, you did this (getting child well). He didn’t get it. That I still have to carry it. I still wake up at six in the morning. I’m the one getting her breakfast. He just takes care of himself and lives his life. He’s not home, he doesn’t come home and say, “I’m making dinner tonight. I’ll cut back a day (at work) so I can make the dinner and get the groceries.” It really is still up to me. “Oh well, I’ll do what you want me to do,” I don’t want you to do what I want you to do, you just need to do it to be done. That’s the distinction.

[I] make breakfast and watch or daddy would watch her, or I would watch her, one of us early in the morning, she’d get to school, this is where the issue is too, that nobody told me that the school needs to supervise. I would come to work anxious as hell. “Okay, she had this for breakfast, that was 420 calories plus or minus a hundred calories with that because I’m not really sure. Okay, so breakfast was so many calories. Okay, lunch, this is what I’ve packed in her lunch. And I think when I add all that up, that was about 1000 calories there with her snacks and her drinks. And then I’ve got the juice box and then the smoothie. Okay, I added six tablespoons of this, so that’s 620 calories plus four tablespoons of cream, so that was 200 calories. That’s
already 800 calories. Oh great. So, the fruit and everything else was just bonus. So good. We’re up to a thousand calories smoothie. Okay.” That was my day. Oh, I had to plan for dinner, and I went to the grocery store five days a week. Minimum, sometimes twice in a day.

Anyway, yeah, it brings you to your knees. ED finds all your weaknesses and exploits them publicly. I lost my mind. I lost who I was. A sense of being. All I do is go to the grocery store. I can’t think in bulk anymore, from a grocery perspective, because I can only get through one day-slash-one meal at a time. It’s been two years, but what can you do? [I] live and breathe and poop and eat, everything was ED. I had nothing else in me but ED. And even though people say, “Oh, you should take time for yourself,” I couldn’t. My kid is going to die. The fact that she gains weight or doesn’t gain weight becomes a mark for me, a grade for me. I am graded on my mothering by her weight gain or loss. Yes! I’m a great mom, she gained half a kilo this week. That could just be me, but that was the other thing. So, that’s how I see it. I’m not doing a good job with my kid if she’s not gaining. I’m a failure. What am I doing wrong? Guilt, shame, blame…

It brought me to my knees. I pride myself on being extremely strong and able and not needing anybody, and just getting it done. But ED brought me to my knees, where I had no tools. You feel helpless. You’re anxious all the time that if you don’t meet that caloric intake that day, your child will die. It’s as black and white as that, so very simple. But that’s what drove me. I would get anxious about going home and having panic attacks, before I went home, because what would I see? What would I do? How would she get a snack? You do lose friends; people don’t get it. Family doesn’t get it. You can’t go back to that relationship anymore. The trust is broken. They’ve (parents) been blamed that they caused this. They were controlling parents. You do become a controlling parent, when you have ED. So, there’s also that funny bias from a professional perspective that parents become overbearing, because they’ve got a dying kid in front of them. You would never say that about the cancer patient. “Oh my God. Look at how caring and attentive that mother is for her kid, she’s with them 24/7,” but with eating [disorders] we’re on top of them all the time. I know some people think it’s a bad thing, but when your kid almost dies, that is the effect on us. That we do have to be on top of them and nobody
understands it. It’s not that we were always on top of them. They only see that we’re on top of them. It’s a pathological relationship and all that kind of stuff. That’s not true. I haven’t really told many people. When I’m saying, “Yes, my daughter was in hospital with anorexia two years ago,” I wonder if what they’re thinking is, “You’re in a bad home and you’re a bad mother.” So, I’m very, very careful. I haven’t told most people much, but also realized, for me personally, those people were peripheral friends. They really weren’t friends. None of those women ever reached out to me and said, “Hey, how are you doing? What can I do to help?” Not one.

You’re going to have to change your parenting style, and it’s not going to be comfortable. There has to be a transformation where you go from a collaborative parenting style, [to] one of “benevolent dictatorship.” I think this is a big “Aha! moment” for a lot of people even on the (F.E.A.S.T) forum, your child has to feel distress. You’re not here to make it easier for them. You’re not here to calm them and control them. You’re here to get the job done. You have to have the distress; you have to have the anger and the upset. But, yeah, brought to my knees. Depression, anxiety, having to carry my husband, my older daughter who thought now that my youngest daughter was in the hospital, she would go and tell the therapist at the family meeting what a bad mom I am and I need to call children’s aid on myself. The anxiety, the sleeplessness, and PTSD obviously, we don’t talk about the aftermath either. It is PTSD, in perfect definition. I think in the aftermath of ED, people don’t know who they are. I did have to seek out a therapist who helped me. I’m really sad, but I’m working through it. I don’t know what more to do. Maybe I need meds. Maybe I’m depressed. Maybe it’s a clinical depression. I don’t know. I know [the ED therapist] told me to cut back to maybe half time (work). I can’t, I can’t, I need to make money. That’s the only place I’m worthy. When I had the capacity, I could see 40 [clients] a day and I am never more than 10 minutes behind, ever, in my office. My work is always up to date. But [the ED] is where I couldn’t be the perfectionist.

It was painful, it had to break me down. I lost myself. I’m still trying to figure out who I am, in this recovered world. Things I used to enjoy. [I] probably gained some weight, and I feel, it’s neither here nor there, I want to kind of get back to my exercise from a mental health perspective. Yeah, I lost myself. I love jewelry. I haven’t worn it in two years. I keep thinking,
am I punishing myself by not getting my jewelry and wearing it? I don’t know. Is that a manifestation of depression? I don’t know. I didn’t want to buy clothes for a long time. I [used to] spend a lot of money and time on clothes. I lost myself. There’s nothing more important than your physical health and mental health. For me, the reward was once a week on the scale. That was enough. It was hard. I didn’t do well. I did not take care of myself. Even if I had an hour break, I couldn’t even get up and do a walk. There was no such thing as self-care for me. I couldn’t do anything else. I am someone who is able to forego pleasure, deal with the shit first. That’s always been my goal. That’s just the way it is, delayed gratification. I can do that and just wait. It [did] not just take a toll on my mind, but my body, so. You’re only a head and a brain. That’s all you are. You’re not even human anymore.

But I’m at a point where I feel I’ve done everything I can do in life. I’m done with life. I’m not suicidal. No. But, it’s okay to die now. But not in a good way. Not because I’m happy. But because I’ve had enough. There’s very few things I find pleasure in. I hate food. I hate it. I’m tired of food. There’s nothing I crave or want. I’m tired. I get up at 5:30 in the morning to make daughter breakfast for six. Then I get ready and it’s always about that. Did I make her lunch? Yeah, I did. I got the hummus out of the fridge. Okay, I did do that. So yeah, that’s lunch. After you and I meet, I’ll be going to the grocery store and thinking about dinner. And that’ll just be for today, ‘cause I can’t even think about tomorrow. I’m not suicidal, I’m not homicidal. I have no means. I’ve had enough of life. I’m tired. I’m done. I don’t find any joy in anything. [A] plain old boring day is the best day. Something as simple as going to work, coming home, having dinner, reading a book. It’s so good. That’s bizarre. I just want a plain old boring life. She’s eating well and gaining, doing well. Pretty happy. It’s all I want.

I don’t know what it is, but I think it has to be spoken [and] repeated. “How are you today mom?” Not, “How’s your kid doing?” “How are you today, mom and dad? How is your marriage? How are you sleeping?” I’m going, “Don’t you know what I’m going through? Do you really know what I’m going through? I live, breathe, eat, poop. I don’t sleep anymore. It’s ED, ED, ED, I go to bed, I look at my phone looking at F.E.A.S.T. I wake up saying, did someone respond to me (on the forum)? Did somebody outside in the world care enough about
me to respond to me?” That’s what you were waiting for. Someone [to] take knowledge of the shit you went through.

I still think it’s flying-by-the-seat-of-your-pants therapy. It’s throw-me-off-a-cliff therapy, it’s like go without a parachute, but you know best. There are aftereffects, and I don’t know if people look at them. People should have been giving you links to videos, nobody did. It was just here if you want to. Here’s a piece of paper, if you want to. Not you should and have to, or I’ll sit down with you and we’re going to go through this together, because I know how scary this is for you. Nobody does that. I think a lot more handholding needs to be done for parents with respect to education, and the resources that they have at their fingertips. You know something’s off, Oh, she’s just leveling off on the growth curve. She can’t keep gaining 100 pounds. I know that. I know that. But it’s not making sense. 4,000 calories a day, something’s amiss. The pediatrician is like, “Oh, I’m okay with it, give her more autonomy.” Really? I’m like, “Losing weight and more autonomy does not mix.” So, I just said, “Oh yeah.” I nod my head and do whatever I want anyway. A few weeks ago, I told my [colleague] “I think I’m going to have a nervous breakdown soon enough. I just don’t know when it’s coming. I just feel it coming.”

Everything I thought about food and health was out the window. I thought about everything. Anytime someone would say something, “Oh, I’m watching what I’m eating,” I wanted to slap them. I would cry at the drop of a hat if I saw a thin child. Just so much anger, so much rage that this was in my house. So much shame. I am burnt out. More recently, we haven’t really had a break. It’s lonely. It brings you to your knees. It takes away all your self-confidence as a person that I can’t even feed my child. I can’t even think beyond this day when it comes to some of that (future thinking). I don’t need to know what my next year is, I need to know my next step in this moment right now, and I’m dying right now.

I have to say like, after this experience, empathy, compassion, is through the roof and something as simple as, oh my God, I got a nap today. You’re so grateful. I always felt extremely strong, able, invincible, yes it brings you to your knees, it’s powerlessness. I think there’s much more compassion for anything anybody’s going through, be it in my work, be it in life, when you
meet other people, like friends in a social gathering, there’s that compassion. I’m invincible on this. I can handle anything. But not in a happy way. You do what you have to do in that moment and then at the end, you have to pick up the pieces of what’s broken. Or throw the broken pieces away.

**Listening to Adrienne.** Adrienne’s story makes me furious, followed with a hollow sadness. Before I even met Adrienne, on her consent sheet she had written down some references for my research, things that would give me some pre-insight into the mother experience. Her story construction began right away with my thoughts of, “this is a woman who knows this stuff, she’s done her research, she’s got things to say.” Adrienne’s story was easy, in the verbal sense. She was clear, concise, she had reflected on her experience and had given it thought. What wasn’t easy were the emotions that came up for me when hearing her story. I felt rage, shock, and sadness, and variations of those emotions with different intensities as she took me through her timeline. I also felt immense shame, as someone who was a clinician and has most likely contributed similarly to negative experiences of the kind that she has had.

I met Adrienne at her office; I got to see her in the space where she felt the most competent and worthy, yet she was talking about the experience that shook her to her core and shattered her self-worth as a mother. Here is a woman, sitting behind a desk full of academic papers, telling me she that had no idea what this ED was, and feeling lost. I’m lost, just as she is at times, between the professional self and the personal self. Her story makes me wonder what is the most effective self at getting service providers to hear her needs: the mother-self or the
professional-self? I wonder, is it a curse or a blessing to have this career-knowledge? Has she a more valid voice when communicating with professionals? Regardless, she still was not heard.

It made me furious to hear her speak of the treatment she faced from the specialized hospital, the assumptions her local ED team made about her knowledge, the time and effort it took her to acquire information. While furious, I was also feeling a sense of deep shame. I like to think that when I was in a clinical role, I gave moms all the information, education, and knowledge I had. But now I’m left wondering what gaps I created for mothers in this role. What assumptions did I make about mothers’ knowledge that may have made them feel unsupported or uncertain?

My shame turns to a place of trying to understand why the service providers didn’t give her all the information she needed. I start to move away from Adrienne’s experience and think, “I bet these service providers are burnt out.” And now, I’m disappointed with myself. How could I just leave Adrienne’s experience and move my thoughts to validating the experience of service providers? They are burnt out, for sure, as I was, but Adrienne is burnt out too, and all she wants is information to reignite her flame of motivation and to keep her moving and informed through this incredibly challenging experience. I am mad at my thoughts and how they interfere with the co-creation of Adrienne’s story. Not my story, not service providers’ stories. I have to do this frequently through my interviews with Adrienne – stop trying to understand what went wrong, stop trying to problem solve, and just listen.

When Adrienne tells me, “It’s okay to die now,” my heart sinks. It falls to my feet, and I just go hollow inside my body. This is a mom who, in my eyes, is educated in a field relevant to
eating disorders, she has read up on current research, and she understands what FBT is; she is what I would call the epitome of a “FBT-role model mother.” She eats, sleeps, and poops everything to do with the eating disorder. And now, when she tells me she’s ready to die, this is not the empowered mother I thought I’d encounter by reading what she wrote on her consent form. I assumed this would be a mother who knows what she’s doing, her kid is improving, and she is feeling on top of the world: she is successfully returning her daughter to health! Not many people can say they’ve done that! So why doesn’t she feel empowered? There wasn’t a joyous, “I have knowledge to share! I’ve cracked the code! I’m successful at this!” It is, as she said, “not in a happy way.”

One of the challenges I faced when meeting and hearing Adrienne’s story was the split of the professional self and her knowledge, and then the mother self and her experience. But perhaps these two cannot be split or separated. Perhaps they inform each other. I need to stop speculating. This brings me to the experience of what it’s like to participate in the co-creation of Adrienne’s story. Participating in this story creation makes me incredibly uncomfortable. In fact, I don’t even want to write my reactions to her story in fear of tainting it, misconstruing it, or portraying her in a way that isn’t what she feels is her reality or experience. I’m worried I cannot capture in words what it was like to hear her story. I don’t want to make assumptions about Adrienne. I want to protect her from further scrutiny or assumptions from others. Yet, interestingly, I know through my own experience that this is not a woman who needs protecting. She’s quite capable of standing on her own two feet, despite wanting to collapse.
Mila

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My life was just starting to ramp up again when the eating disorder appeared. I had just gone back to work part time. I had [rented office space]. I was just starting to feel like my head is above water, the kids are okay, everything’s just kind of kicking along. [My husband] and I had started to travel a little bit together. I still had a pretty busy go of things because my dad was sick, but I felt like it was time to look at my life now.

My dad died in 2018, so December 2017 was the last day I was in the [office]. I went all of 2018 without setting foot in that space and prior to that I had not really been in there working seriously because [my daughter] was sick, my dad and my mom needed help, and I was working a couple of days a week at [another job]. I just found that that job required my attention and I had to put my [personal] life on hold because of all that. I had to give up my [office space], I was paying $250 month rent and I hadn’t been there in like a full year.

Right around the same time as the eating disorder happened, I had a lot of pain. I started going to the doctor about it and they discovered [autoimmune disease] so I was like, “oh shit that sucks.” I stopped everything. I didn’t go back to the doctor, the [specialist] was in [another city], I cancelled all my appointments, it all felt so overwhelming. My whole health, my well-being, I stopped exercising because it’s difficult to go exercise when your daughter has an eating
disorder. I stopped baking, stopped doing a lot of the things that used to bring me a lot of joy. I stopped looking after my health, I stopped work. We were seeing a nurse practitioner and dietician, sometimes 3 appointments a week plus our own counselling for FBT, and you’ve got the other two kids that you’re looking after. It just felt like the very last thing on your list is your own health and the other things that stopped, like, for the other kids you try your hardest to make sure nothing changes.

[When my daughter was diagnosed] we told [my husband’s] relatives but didn’t tell mine because my dad [was sick] my parents lived in [a different city], my other two sisters live in [another city], I was their primary contact. My mom has [an inflammatory] disease, my dad hadn’t been doing well. I knew that if I told my mom that [my daughter] had an eating disorder, she wouldn’t call me, and she needed me: “I can’t bother her.” I didn’t want that to be a part of the equation. I didn’t want to feel angry at [my daughter] and I didn’t want [my daughter] to feel guilty that her illness was getting in the way of my mom and dad and their needs. There’s a lot of emotional managing. I was doing both and it was killing me, it was so awful. I remember once when my mom had bowel obstruction and I get the phone call at like 11 at night “I think I’ve got the flu.” My dad couldn’t get out of bed, he was completely immobile. I remember driving and [my daughter] is sick, like really sick, she’s hiding food, she’s chewing and spitting, she’s weighing herself all the time, violent, angry, like aggressive towards me, like, bloody nose, punching me, kicking me, I had a charlie horse for a week, bruises.

All of that’s going on and I’m standing at the end of the bed at my parents’ condo thinking, “Okay, my mom has to get to [the hospital], my dad is immobile and can’t be left alone.” Being in that position, three people needing you and pulling on you, [you] don’t even think about your other kids or your husband. I thought, “I think I might have a panic attack; I don’t know how to do this.” It can make me feel tearful right now, it is like PTSD. Then the day [my dad] died, it was terrible. I saw him the day before he died, but [my daughter] tried to commit suicide the day he was in the hospital, so I was in the emergency room on the phone with my husband and I was like, “Oh my god what am I going to do?” I had to leave [the hospital] and then he died the next day.
It’s like PTSD because I get a little bit emotional about it and it’s weird, I think the experience is strange because you don’t normalize it, but you accept it and how do you accept that? Because we’re taught societally not to accept this behaviour, and you feel ashamed. The [ambulance coming to my home in response to my child’s suicide attempt] is shameful. Like how much lower do I have to sink? This was not where I saw myself being. I thought of myself as being fairly successful and educated and I had my shit together. I’d stayed home with my kids, and there was guilt there. I stayed home with my kids and this is what I’ve created? There were times that I’ve felt like there are all these other people who managed to have careers and families, their kids are not in this position right now. I really was so devoted to my family so there was an enormous amount of shame that F&CS was involved, and fear. “What if I’m in la-la-land here and I think I can manage this?” and [F&CS] come in and go, “Your [other child] is really not managing and we don’t think you’re doing a great job.”

I certainly got angry. I certainly raised my voice and said terrible things. You think, “How can I say those things to my daughter?” [My daughter] took [out] a lot of physical stuff on me, maybe because I was there? I wasn’t fighting back in those moments. I became very [passive]. I don’t know [why], because I thought I would hurt her? Also [my husband] would step in [and] be the first one to block the punch or get in the way of that. He was there but often he’d be like, “I can’t take it; we can’t do this.” That part really upset me, he’d be like, “I can’t take it, I’m done,” which I know is a normal reaction when he’s overwhelmed. He was like “nothing I can do about that,” just very black and white. It puts a strain on the relationship. There were times when I was like, “pick it up a notch.”

There are times when I’m resentful that [my husband] can’t do more emotionally, but I guess I always managed the emotional side of things. There were places in our lives that he was absolutely reliable, but when it came to the emotional piece and doing all of the stuff that we were being taught to do through counselling he found that really hard. He just wanted someone to fix this. I couldn’t go to [my husband] with these worries because it would send him through the roof. He was already at a high level of anxiety; it was too much for him. Then I would get
angry if I went to him specifically to say, “I need help,” and he couldn’t help me I would be cross.

We had really divided up our marriage in a way that was pretty old fashioned. I was at home with the kids, and he was at work making money. He’s not a hands-off dad but it’s just a different role. I would say that he was fearful and didn’t want to do that kind of heavy emotional labour, so that piece fell on me and I think I was surprised that so much of it fell on me. I thought he would rise up to take on half of it, and here’s more guilt because I’m now at home full time. I was working part time and [then] I took loads of time off work. I felt like again this is my job, I’ve got to be the one to do this because I’m the one home more than [my husband] is and he’s working and he’s tired and he’s staying up till all hours and he still has to get up and work and he’s a [high position at work] and he’s got responsibilities and, you know, I felt like I could do it all.

I shed some tears with [the ED therapist] because I was so overwhelmed by [my daughter’s] suicidal tendency [and] with what was going on with her care. I was home 24 hours a day again, and I was feeling sorry for myself, like I’m never going to get back to what I wanted to be doing. I totally love having kids. I’ve made many choices in life that focused on family before other things, so this wasn’t a new thing for me, but it was still a hard thing. I felt a bunch of different things, one of them being like “no problem, I can do this” and then the other side of me that was like, “how the hell did I miss this?” and the shame, lots of shame. I’d stayed home with the kids when they were younger and I felt like, “what have I?...” like they’re an extension of you, like if my kids aren’t doing well it’s something that I have done, it’s something that I am responsible for, so feelings of guilt and shame. Interestingly enough, my sister had anorexia. I knew the signs pretty early. There are times even now of guilt that I didn’t see it early enough, or I didn’t react to the anxiety. Guilt that I didn’t step in earlier, give [my daughter] some skills. Even though my sister had an eating disorder, we were never part of the therapy, we were kept very outside of the eating disorder. I witnessed it and I experienced it [as a sibling] but I didn’t have an outlet and I didn’t understand it, and there was no repair made. I know I have a lot of work to do on that eating disorder [with my own sister].
It was a year of up and down. That’s the hard part, too, that there [are] days when you think “everything’s ok,” like where I am right now, I think, “oh, we’re going to be ok.” But I don’t know because she’s not here. I honestly didn’t think I would get through another day [when my daughter was home]. I wasn’t sleeping, I’d lost weight, I was overwhelmed with anxiety, I said to [the ED therapist], “I have never felt like this, ever in my life where I don’t feel particularly safe, my thoughts are abnormal.” [I’ve only shared this with] [ED therapist], thank god for [ED therapist]. I’d never lost so much faith. It was in extreme moments of stress where I was like “I don’t know how to go forward.” It only happened twice where I was really feeling like I don’t know why I’m here. Not really suicidal thinking but “this is overwhelming, and I don’t see a way out of this, I can’t maintain this level of anxiety or distress.” It’s weird to feel like you’re in a room without a door. Like when does this end? When have I hit rock bottom? Everybody says, “You have to hit rock bottom,” I felt like I hit it last week, why am I still falling?

I was feeling so overwhelmed. [My husband] would get home, we’d have a quick bite to eat, [my daughter] would have to go out to a program. So, at that point in our life everything felt overwhelming. The things that didn’t feel that they weren’t absolutely necessary got dropped and now I see that, now that [my daughter] has been in residential care we can go “wow [our other child] doesn’t know her multiplication and division.” You stop paying attention to some of those things that don’t feel that crucial.

I was hesitant to look at residential hospitals, but it was really the only option because I had to be home with her 24 hours a day, she wasn’t going to school. [My husband] said, “I think we should put the application in.” I said, “What application?” I was like “No, we can do this, we just have to double down, we can do this” and he’s like, “No, we can’t, and I don’t want to.” I was angry, and around that point I started to think, “oh maybe we can’t do this.” I started to feel a sense of failure that I had not managed [at the local ED program], and if I could go back we would be able to keep her at home and we would be able to solve this problem and then it just got progressively worse and worse and [then] I was like, “Yeah we need this, we got to get her out of here, this isn’t working.”
I got to the end. [I thought] “I can’t do it anymore.” Then after you get her into this residential treatment program, and she’s locked up and you think, “Why is it this way? Why do they not tell me what’s going on?” My anxiety didn’t really get any better because she was calling us from [the residential program] freaking out, crying, every day. We had minimal information still at that point, this is like three weeks into the program. Those administrative issues have made the admission into residential care very difficult and have added to the anxiety and the stress. You kind of think, “It will be great, I’ll be able to get a bit of reprieve and my daughter’s going to be getting 24-hour care immediately when she needs it.” But it’s not that way, and that was difficult. I have all my eggs in this basket, but I have a lot of anxiety when I dig into it.

[When] I am in distress, I get into take charge mode. I start ordering people around. For example, [my daughter’s] calling me from [the residential program] freaking out, wanting to kill herself. First off, I’m mad because she’s calling us and there are staff there and no one is helping her. Where is everybody? And then I say, “[Husband], get on the other phone and call one of the nurses because she’s in distress and they need to be in there helping her,” and then I’m like “[My other child], go get your stuff on.” I start ordering people around, but the end result is to isolate myself. I couldn’t call anyone; I couldn’t reach out to anyone. “I want to call you, I want to share but it’s overwhelming, like I can’t even pick up the phone to do that.” I think it’s an interesting pattern that I get myself. All this softness is kind of gone from the edges, so, still very much emotionally there, but there’s no grey area. I was meeting with [ED therapist] regularly, trying to figure out how do I talk to [child] about her killing herself?

My role, I feel, is in advocacy. I feel nervous in this role because my daughter is in a locked facility where she is at the mercy of [other] people. I don’t want to make it bad for her there. I’m constantly saying to myself, “Is this me? Am I such a perfectionist that my expectations of the program are too high?” I don’t have any benchmark to measure it on, the only place I can go is internally and being critical of myself. Am I balanced enough? Am I wanting too much for her? There’s this rumination that goes on as a parent, like what am I doing? What piece am I bringing to this puzzle that is positive or negative? I’ve said to [ED therapist] before,
I’m like, “Maybe it’s because I have more control through FBT than I do here (residential treatment), maybe it’s like a control issue,” and she’s like, “No.” I’m disappointed with that (how the residential program did not have much communication initially), but it’s respite, we know she’s safe there.

I’m trying to be very balanced. I’m constantly emailing. I’m trying to be careful. I think [the residential staff] think of me as a shit disturber. I think they think I’m neurotic, or super controlling, critical, you know, all of the characteristics that they used to use to blame moms. I know I am a perfectionist; I know that I am controlling; I can be all of those things; however, I am quite reflective, and I am willing to give over control, but this is my daughter and I feel like they keep screwing up, so I don’t trust them totally. I’m trying really hard to be involved in a constructive way.

The first Christmas when we entered into FBT there was a friend outside of our circle who invited some families up to their cottage for New Year’s, but we didn’t get an invitation. [Friends of ours, who we usually spend New Year’s with] did and they went away to this cottage. I have never been more devastated in my life. It was so painful and that was a hard thing to share with [the friend]. I mean, we felt so isolated and also sort of cheated. Like, if [child] had cancer no one would have left us out of that, it would never have happened and so it was very devastating. That was a very hard Christmas and New Year’s.

Now, I can finally address some of my own health issues. I’m grateful I don’t have to worry about getting a text from [my daughter] saying, “I just want to die.” When I actually get to the meat of it, I want more. I don’t know what the next steps are, I’m trying to prepare for that. [When] she was first admitted into the [local ED] program I thought I [could] look down the road and see the end. Then I got to [the residential program] and I thought, “Okay this is going to be the end,” but it is scary to not see an end anymore. When you are sick and you don’t have a diagnosis you worry, then you get the diagnosis and you feel hopeful and then treatment happens, and it doesn’t necessarily help and then you lose hope again. It’s this constant up and down and sometimes I lose hope again or I think a year from now we’re going to be good, but I don’t trust that anymore.
Right now, it’s easy to talk about these things because she’s in care. If she was lying here [and] hadn’t been to school because she couldn’t cope [it’d be] a different story. Could I kick her out of my house? Could I say, “You’re 21 years old, you’re still ill”? I’m afraid that I would keep pouring into [my daughter’s] care forever, at great loss potentially to my health. I see [my role as a support] going on and on forever, but I am really trying hard to let her make stupid choices. I can’t stop her from taking her own life. If she wants to do that, she’ll do it in the ten minutes between me being at work and coming home. It will be devastating but people survive somehow. It is a terribly dark thought [but] I recognize that there’s only so much I can do.

[It’s] hard for me to not have a direction. Not that I don’t have a direction, but to not see a pathway. With a mental illness or with an eating disorder there’s no path that you can follow. You need to sort of take a lot of that framework and abandon it. You have to have some kind of blind faith. It doesn’t feel like it is a straightforward trajectory, so that is overwhelming. I have to get somewhere, I know I want to be making money, I know I’m heading somewhere, I just don’t know what’s on the dart board and that’s ok. I had a vision three years ago: I’m going to get my [office] up and running, I’m going to start making some work. That’s my dart board. I had that three years ago, then the eating disorder and now [my own health issue], so, I’m just starting to feel like I’m moving towards getting my health in line, figuring out what I need to do to maintain my health, and then I’ll look at what comes next. I think that’s how I feel like I’m approaching it.

The future is uncertain. I want somebody to [be] able to say something at my [funeral]. That’s really what your life gets boiled down to. Does it matter that I don’t see myself as having had a career? Sometimes it does and sometimes I feel like the eating disorder has certainly gotten in the way in the last two years but prior to that I was just starting to get back into, like “Okay I’m going to make some work.” There’s a lot of change on the horizon and I don’t know what it means.

I think I am changing. I think I am really trying hard to appreciate the present. You know, my house never used to look like this. I’d say communication has changed for me across the board. I’m much more direct and I feel like the lines, the boundaries are a little bit clearer with my mom. Our roles as moms evolve, this is why this whole eating disorder and FBT is so
confusing. When the eating disorder happens, you’re right back, it’s like snakes and ladders, you’re back at the very beginning going through all of this stuff again. “What do you see on your horizon for your future?” I would love to find a role for me in this. I don’t know in what capacity, but I am fascinated by the whole eating disorder thing. I really would love to be able to help people through some of these things.

I’ve thought a lot about what really matters because I’ve been struggling to find meaning in my life. Am I going to leave a mark in the world? It opens up bigger questions. I feel like I can’t move forward until I know that she’s well enough. There are moments where I can go back and be grateful for time spent together with [my daughter]. I feel strong and I feel like that is a gift. I felt like “I can do this; I can do anything.” I feel like holy shit, we just went through hell and emotionally I’m resilient, I’m strong, I am positive, and I can say those things really confidently. I think there are people who never get to say those things about themselves or maybe know that about themselves through something that doesn’t have as much emotional connection. You can’t be more vulnerable than when your kids are sick, or your relationships are at stake, or the things that make us human or connect us with another person, and the last two years that’s all I’ve done. I got to experience that and experience a deep love that some people never experience and never even know and appreciate. That’s why I think it is important to me that I have a career, but at the same time I think [of] what I have gone through and what we’ve done is so huge and so hard. This brings me to tears because [my daughter] said to me, “thank you, I don’t think I would be here if it wasn’t for you,” and to feel like you are helping save someone’s life, it’s huge. Lots of people can influence their kids and help and can feel like “Oh I helped my kid get to that phenomenal position in life,” but I think I’ve saved her.

**Listening to Mila.** Mila’s story overwhelms me and has literally brought tears to my eyes. I remember leaving her house, getting into my car, and just feeling exhausted; I had tears in my eyes as I drove home. I’m overwhelmed trying to keep track of her story and overwhelmed by the series of events that have taken place. Growing up, her sister had an ED, her dad died, her
daughter overdosed, Mila was diagnosed with an illness, her daughter goes to a residential program, she is now playing catch up to help her two other children – I’m overwhelmed. I want to scream, “Give this woman a break.” I feel as if she’s lived in non-stop crisis and I’m overwhelmed for her. Even with her daughter now away from the home at a residential ED program, and the crises not happening in person, the mental work that Mila has to do, the questioning, and the planning she was vocalizing, made me feel so overwhelmed; this need to be “on” never stops.

When Mila says, “I felt like I hit it (rock bottom) last week, why am I still falling?” this is when tears come for me. I feel the exhaustion through her words. When she tells me about this unspeakable and shameful violence that took place towards her in her own home, my stomach feels sick. I picture Mila being the recipient of punches, kicks, and threats, and I just feel sick to my stomach, imagining the experiences that this woman has had to face with her own child. Mila spoke of needing to have this “blind faith,” and I get anxious hearing that. I hate blind faith, and I can only imagine how hard that is to have when it’s regarding your own child’s health. I don’t want blind faith; I want answers and solutions.

Mila said that this ED was something she thought she knew, she had an ED in her family growing up, but realized that she didn’t really understand or know this illness in her daughter. This really shakes me to my core. I’ve worked in the field of EDs for almost a decade, and hearing her story makes me feel that I really do not understand, or know, the realities that are being encountered. I think to myself that this level of intensity that Mila experienced can’t be normal, that this violence isn’t typical, and yet, this is Mila’s reality. I minimize the experiences
she has in my mind by thinking that this is abnormal and atypical for the ED world. I negate her reality and find that I detach myself from her experience in order not to feel the overwhelming discomfort of not knowing how to help in this uncharacteristic situation.

I’m also angry. I’m angry that she has to do it all and that her husband cannot add more or find a way to support her and the kids to give her an emotional respite. I’m angry that this sentence is being added in after re-reading what I’ve written and that I continue to add to the narrative that puts fathers on the back burner and removes them from responsibility, that this is all on Mila. He is part of her narrative, but not able to contribute in the way that Mila does. I’m tentative in writing this because I’m not sure how Mila would want her husband to be viewed. I imagine being the sole provider has its pressures. I’m mindful not to blame him, but angry that she really does shoulder the responsibility for not just her daughter with the ED, but her other two children, and her own extended family.

I was, and still am, anxious in the co-creation of Mila’s story. Even during the interviews, I would arrive at her home with anxious feelings, wondering how her week had gone. Had her daughter come home over the weekend? What information will I hear today, and how has her daughter coming home impacted that? Mila’s story reminds me of a choose-your-own-adventure book. It’s rife with uncertainty, unpredictability, and it’s non-linear; like she said, “snakes and ladders.” When Mila speaks of her future of where she feels she should be, where she wants to be, and then looks at where she currently is in life, I feel her frustration for the future. I hear her story and know there is still much to come, and thus even thinking of a future is only in regard to
her daughter, as she said, at the expense of herself. I’m amazed by this woman, but incredibly sad hearing what she’s had to experience, and what she’s had to give up.

*Rina*

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I think the pain, the chronic pain and the anxiety and everything I think that’s what started it. She went away to camp and came back, and we had been doing all this stuff for her chronic pain. [When my daughter came back from camp] she was really anxious. And we weren’t sure; was it the pain? Was it the experience of having the headaches and having to handle all of that stuff on your own? You know, that sort of thing. We had an appointment with the pediatrician beforehand, and she started having anxiety attacks. So, I was proactive about getting her on something. We got her on some medication and that helped even it out a little bit with the whole anxiety thing. But she had started to lose weight in August. [At the chronic pain program] we [were] tracking weight changes. So, [she] started being like, “Oh, do they always have to weigh me? I hate being weighed.” I’m like, “Honey, everybody hates being weighed.” Thinking nothing of it, right? [In December] I had noticed she started to lose a lot of weight, and it was concerning, and I was really watching what she was eating and being like, “You need to eat a little bit more.”
The nurse (at the pain program) said, “You can’t lose any more weight. You need to stay where you are right now.” And I’m like, “Okay, this is really weird.” The nurse practitioner called me, and she’s like, “I’m really concerned.” That was when we got referred to the eating disorder program, and so we just had to wait for referral. Our pediatrician really seemed kind of clueless. I don’t even know what to do, and I’m trying to deal with all of these emotions on top of her being a teen. Between sort of Christmas and New Year, [and] our appointment in January, we kind of stabilized her weight. But then, between January and February, it dropped again. Her emotional ability was… she was very negative, she was very low, she was very anxious. The self-hatred is just the worst. People are like, “Oh, well all teens are like that.” You’re like, “Yeah, this is that on crack.” Every parent thinks that you know your kid. Everybody does. Like there’s a part of me which is like baffled that she could lose 30 pounds, like I’m baffled. Because I supervised the food, I made lunch, I made breakfast, I made sure she ate breakfast but I’m just like, “Wow. How did that happen?” You think to yourself, like, “Was I clueless?”

I was at my wits’ end. I’m like honest to god, how is this happening? I was really watching her, and that’s when I noticed certain behaviors. You know, that she was edgy, that she was doing exercise in her room... she got really agitated. We’re just at the beginning stages of getting her to put a few pounds on, so you know, how do I deal with that? How do I get her past that? I think there’s a general lack of in-person connection between parents. I don’t know any other parents who have this problem, so online has been a really good resource. I’m part of a couple of online groups, and I hear what some other parents go through, and think, “Holy shit. Like, I’m so lucky.” Because she’s a pleaser. She wants to conform. She’s a ruler follower, so she wouldn’t just refuse to eat completely. But I don’t think I would ever let it get to that point. I’ve never given [my kids] that power over food that they would get to a point where they’re like, “Well, I’m down to eating nothing but yogurt.”

You know, we’ve already got our shit together, so maybe that’s why it’s not nearly as wrapped around. I think families need more because it went from being the parent’s fault to the parent’s responsibility, and yes, as a parent, it is your responsibility. But it’s a heavy weight. I’m not working right now, thank god. […] I [just] wrapped up a job and thank god because of all of
WOMEN’S NARRATIVES: COPING WITH CHILDREN’S EATING DISORDERS

this blowing up. I don’t think you could do a full-time job in this. You have to be very proactive, on your own, to source information. Like, you have to be doing a lot of work. There’s a lot of pressure on parents to source out that information. There’s not a lot of knowledge out there in broader society about it, either, so how do you deal with it if you need to talk to the school, or that sort of thing? I had no knowledge. We knew about eating disorders, but you don’t realize how significant, how ingrained it is. I never really realized the significance, that it was so heavily rooted. There are days I say to myself, “I’m not dealing with the kid. This is not [my daughter]. This is the eating disorder.” They’re not being themselves, and so you have to learn not to get frustrated with that. That’s a big thing. And you feel terrible that it’s something that they need, they physically need this food, but you making them eat it makes them upset. And so, in basic terms, you are making them upset, because you’re making them eat. But on the other hand, it’s not you at all, it’s the fact that their messed-up eating disorder alien is popping up.

You need to be emotionally supportive. But on the same hand, you still have to make sure that you are that parent. I imagine some parents must have a hell of a time. I’ve always been a parent. I’m not there to be their friend. I love them, I’m supportive. I give them a lot of space to make mistakes, but when I say no, I mean no, and there’s no discussion. I’ve never been a permissive parent. [My ex-husband] has a harder time. My ex is much more permissive. He’s not as on top of it, ‘cause I’ve always done the parenting. I made the decisions, I handle everything. And so, [my daughter] pushes much more, and she’s always been able. I remember saying to a friend, “If we can’t get a handle on this weight, I will make [my daughter] stay with me.” And I would make that call and I know [my ex-husband] wouldn’t give me a hassle about it. He would probably be like, “Okay, yeah, I get it,” kind of thing. So, if push came to shove, I would definitely go that route. That’s definitely an additional stressor, just being concerned about what they’re doing when they’re not under your supervision.

I think there’s a lot more pressure [in the treatment]. I expected a lot more detailed information. A lot of it is very much up to you as the individual how much you choose to get information. It’s almost like you need an intensive one-day session where you kind of come in and they tell you, “Okay, this is what it’s going to be like as a parent on the Maudsley Program.
Here’s how it works out over the time scale. Here’s how it looks like progression wise. Here’s some of the things to expect from your child.” You know? “Here are some behaviors you may see happening. Here’s what you need to be aware of. Commit to this.” I think that probably would’ve been very beneficial. I didn’t feel like there was a lot of that. I felt like it was very much like you went in, they tell you about the program, here’s a book you need to read. It’s almost like they service this third-party tab, honestly. I feel like it’s more like they’re keeping tabs on [my daughter], and I think, for me, it probably has a lot more to do with who I am as an individual, because I’m an information seeker, I’m going to source out a lot more support. I’m going to look for as much information as I can. I think for me that’s the difference, is that I had that information. I’m already very knowledgeable about nutrition and that sort of thing, so nothing was really shocking.

That’s the problem. They don’t give you a trajectory, and I think you’re flying blind as a parent, a lot of times. I guess flying blind isn’t the worst, because you know you have the same job every day, and that’s to feed them and get them to eat. But it’s the fact that everything else that is surrounding that feeding piece, the feeding is the easiest part. It’s the emotional stuff that is not easy to deal with. It’s the reactions to the feeding. It’s the emotions that it brings up in yourself. It’s the anxiety that the child feels. It’s the behavior, that they’re going to seek out to avoid that feeding. It’s the worry. Are they purging? How do I know if they’re purging? How do I find out? It’s bad enough that I feel like I’m flying blind, and I have way more resources and capacity than the average person, so I can only imagine what other parents feel like, so I keep reminding myself. I’m very lucky. We’re doing okay. I haven’t lost my mind yet…. But I worry too. My worry is okay, I’m off work right now, but… what’s going to happen when I find a new job? What kind of supports am I going to put into that? You know, am I going to have to hire someone to come to my house after school and make sure she eats?

[ED therapist] is lovely. Like, she’s the nicest person. She’s so gentle and kind. She doesn’t take crap, so she doesn’t have a problem telling [child], very nicely, “Well, that’s not the way it’s gonna be. You’re gonna have to eat.” I’m saying the same things that every other mental health professional is saying, helping them to say it to her so that she gives it more legitimacy. I
think I expected more involvement with the nutritionist, and even the nurse practitioner, in terms of them even interacting with the child. I really feel like all of that stuff is really left to you as the parent, so they aren’t providing therapy for your child. You go in for your weekly or every 10 days check-in for your weigh-in and stuff, and they spend an hour with you, and they kind of talk about how you are, and they maybe make suggestions. But it’s not therapy. It’s a check-in. You’re kind of on display too, which is I think scary. Like, oh my God, stuff that goes on in the privacy of my own home is going to be on display. My kid could bring up anything. Everything you feed your child is open for display, how your child is doing is open for display, and then your child’s interpretation of their experience is, so they’re going to interpret their response to you or, you know, as a parent listening to your child talk about how they’re feeling and you’re like, “Oh my God.” I think that I thought it would be more about the feeding and still being a mom, but I’m not just a mom, I’ve got to be mom, I’ve got to be therapist, I’ve got to be, you know, health coach, I have to be, you know, researcher, dietitian. Just the way that it is sort of infests your every moment, every part of your life.

At the beginning, I remember saying to a friend, “Oh my god, this is triggering me so much.” It was really stressful. I felt really high anxiety in the beginning, just because of this obsession. All of a sudden, I had to be obsessed with food again. Instead of food being a resource, instead of food being about giving you energy, food was about, “I have to analyze everything.” I’d worked so hard for food to be about, “I’m hungry and I need fruits and vegetables, and I need grains, because I need energy for my body,” to being obsessed about, “Well, what is the caloric content? How much fat is there?” You know, “Does it have this in it? Does it have that?” And that’s a huge change. I’ve always been cognizant about the nutritional value, but to have to be obsessed to the point where you’re almost calorie counting again is stressful. I grew up [where] food was a controlled substance in our house, and my mom was an obsessive dieter. And so, when I had kids, I was very much different than that. It was you can always help yourself to fruit and vegetables. I was always about, “Well, you know, one glass of juice a day is fine, but we eat our juice, we don’t drink our juice.” Now, looking at all of the reading, I’m like, “Holy crap. I probably would’ve fallen into those eating disorders, where, you
know, the binging disorders for sure.” It took me years to get to the point where I could be like, “I’m okay. I don’t really want that.”

I’m emotionally invested in her wellness and her success, but on the other hand, I have to hold my own emotional stuff back. I cannot let her know how much it bothers me because that’s a weight that she can’t carry. They’re already the kids who are worried that they’re a burden, or it’s too much, or they’re stressing you out, or that sort of thing, they already are that type of kid, so I have to be careful. I have to be a more filtered version of me, I’m much more cautious about what I let get to her. That’s the hard part because as a parent we could be falling apart but you don’t get to fall apart. It’s like when you’re sick and you have a kid and you’re like, “That’s nice that you’re sick, but you’re going to make lunches and get everybody to school.” And that’s part of being a parent. If you want to fall apart, fall apart, but don’t fall apart in a way that your kids can see it. I think because I’m not working right now, I’m able to manage and contain [my emotions]. I have the time. Whereas if I wasn’t, I think I’d be shitting my drawers.

That’s the lucky thing, that I’m not working right now, so I can have that time to invest in [treatment]. It’s that emotional labor, right? It’s that that they always talk about; it’s the mental exhaustion of always thinking about, “Well, has this happened?” Making sure that the kid has eaten, that lunch is made, that they take that with them, that when they come home, they have a snack. They do their thing, making sure the dinner is eaten, then you’re thinking about your next snack, and so it is; it’s a very labor-intensive process and I don’t feel like there’s quite enough supports for the parents. You know, there’s lots of information, but there’s not enough clarity. I guess everybody’s different, but even saying, you know, “Every snack should look like this. They need to have these three things, or these two things.” Even things like that would be helpful. It feels like there’s so much left up to parental discretion that that’s the exhausting part. There isn’t enough specificity. It feels like there’s a lot of talk about theory, and the books that they suggest are really good in that sense, and you really understand the thought process behind it and why, but it’s very much on the family. It’s your job. Like, “Get at it.” And if it doesn’t work, what happens? You know, it’s you. You failed, right? So, you go, “Okay, well, there you go. Whose fault is it she didn’t gain weight?” Me, because it’s my responsibility to ensure that
the food is there to ensure that she eats it. It does make you paranoid, especially for me with body issues and food issues, that took to me so long to have a normalized relationship with food. It’s frustrating.

In terms of me, it has been exhausting, but it hasn’t been all negative. It’s forced me to be more self-aware, it’s forced me to reconsider issues that I have and reinforce my own beliefs in body image, and to be positive, and to be encouraging, and to support other women and encourage them to be self-aware and to be positive about their bodies and who they are. I think a lot of people when they’re going through those challenges and if they self-blame, it feeds into the whole, “well [you’re] not a good parent, this happened because you’re not a good parent.” That’s not the way it works. We do the best we can, and shit still happens. You can’t prevent everything. It happens. Things happen. The pressure’s on parents and ... it’s hard, right? We realize that we have unhealthy habits in society on a whole but for these kids that’s not what they need to hear.

It just goes to show you as a parent, and why this whole “blame the parents” is so wrong, because you can do everything right. I’ve done everything right when it comes to food, when it comes to nutrition, when it comes to making sure that I always have helpful alternatives, not having crap in the house, being body positive, not talking negatively. [This eating disorder has been] an educational opportunity. I learned so much from the fallout of that and then also how to get her past things. It happened for a reason. But I think it could really take over your life and be exhausting. You know, I’m still at the early stages, and I can definitely foresee frustration ahead.

**Listening to Rina.** Reading Rina’s story, I feel her confidence ooze out of the words. When meeting with Rina, she had this easygoing, confident air to her. She spoke easily, and if I misunderstood or misheard something, she would correct me without hesitation. I am a bit envious of Rina’s confidence and how clear she is regarding her role as a parent. She has this “take no shit” attitude. When she spoke, I felt confident, but I also felt inadequate. Rina has this confidence and “I can handle it” attitude around uncertainty, or “flying blind” that I do not have.
I’m reminded of myself as a clinician, and “flying blind” with families when I was presented with issues that I was unsure how to handle or support. I would feel incredibly uncomfortable and anxious, scrambling to find answers as quickly as possible. Even as I do this narrative research, trying to trust the process is incredibly painful for me. I am envious of her confidence. In fact, during our interviews I mostly remained quiet because she had so much to say, and with such assurance.

I feel a sense of amazement hearing Rina reflect on her own experience with disordered eating in her own life, and how this knowledge has pushed her to become a body-positive woman who does not wish for food to have the impact on her kids that it did on her. There is also an uncomfortable, gross feeling that comes over me when I hear Rina speak about the feeling of being under surveillance, or having tabs kept on her and her daughter. I feel gross that she feels there is a gaze upon her, making sure she is doing things right. I feel sick thinking of her entering an office, exposing what has been going on during the week, and getting feedback on her performance. Maybe she doesn’t feel that way, but it is what occurs to me when I critique myself as a clinician. When she speaks of the vulnerability that her child could say anything in a session about the private family life and it could be scrutinized. When Rina says she’s not emotional, it makes sense when taking into account this surveillance feeling. I can imagine that a mother needs to appear to be capable of handling the challenges that the eating disorder will throw at her, or else be judged and potentially scrutinized.

This gross feeling leads to total frustration when I hear Rina say that she’s done a lot of research on her own time and effort. The lack of education and practical advice or guidance is
frustrating to hear, especially when she feels that if she doesn’t do “well” in the treatment, the failure is on her. The education is on her, the outcome is on her, and on top of that, she is feeling monitored in sessions. When I hear all of this, a sense of loneliness comes over me. Rina is doing a lot of education for herself; other members don’t totally understand, her ex-husband cannot support her effectively, and she says there is a lack of connection with other parents. It is a curious thing that there hasn’t been more done to connect parents in this context to one another. Why isn’t this part of the treatment? Why can they not impart their advice and wisdom to each other? This makes me wonder why I didn’t encourage parents to connect with each other in person. When I think of Rina, I think of her as a confident parent, and think, “Oh, she doesn’t need any other supports. She’s rock-solid on this.”

Rina’s story, while it evokes confidence in me, and makes me feel that she can handle whatever comes her way, does give me a bit of a reality check when she reminds me that she’s off work right now, and that they’re just in the beginning stages and she foresees frustration. It brings up old memories of people I’ve worked with and how we started off with such hope and confidence, but it eroded as time, and life, went on. I hate that these memories come up and put a damper on the confidence I felt listening to Rina share her story. I’m supposed to have hope for these women.

Diane

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Duration with the ED: 11 months
Duration in treatment: 11 months

Everyone was kind of like, “Oh she’s fine. She’s got a growth spurt,” and I was like, “No something’s going on.” “Don’t worry, you know there’s so many teenagers that look so thin and they don’t look healthy, and they don’t eat well.” [But] as a mom you just know. I knew that she was kind of looking gaunt and not really herself. And then she wasn’t choosing a lot of food. Her lunch was very limited. I would ask her, “What are you eating and how come, when did you eat?” I’d have a conversation with her about her food choices because I’m like, “Why are you eating just these rice cakes and stuff?” Because she was never like that before. She was a junk food junkie for sure. I knew something was going on.

I was making her lunch and her brother even said, “Mom, she only has two meatballs.” So, I said to her dad because she sees her dad 50% of the time, I said, keep an eye on her and stuff like that. Then I ran into a friend’s mom. We were at the grocery store and I had said to her, “I’m worried about her.” She said, “Oh, well she ate a good dinner when she was at my place.” I thought, okay that’s all right. I even said to my son, “She’s not eating a lot. Keep an eye on her even at lunch and stuff.” I messaged her dad and said, “I’m going to make a doctor’s appointment.” I couldn’t get in for a couple of weeks and I’m like, “Yeah, this is not okay.” I just ended up taking time off and said, “When’s your next available because I think my daughter has an—” I don’t even think I said eating disorder. I said, I think she’s got some issues. She’s not eating, and I think there’s some stuff going on.

[The pediatrician] weighed her and kind of looked at everything and asked her questions then said, “Do you know that you have an eating disorder, honey?” Because she was 94 pounds. So, she went in [to the local ED program]. We met with [the ED therapist] and a couple of the counselors there. [The ED therapist] said we have to refeed and stuff like that. Start refeeding,
making sure she’s eating, and you have to supervise her eating. That was hard because you go from... It was like all of a sudden you had this newborn again that you have to cook all their meals.

It was crazy when I look at it. She had a cup of milk and she threw it all over herself because she was so frustrated and anxious. She threw it all over the kitchen, too. “I can’t eat.” She was getting so upset and angry and anxious because she was being forced to eat something. That was scary because my kid... I was like, my god, who’s this kid? This is terrifying. At [work] I’d be hearing about all of these issues that were going on with some [other kids] and then it was like, “Oh God, this is, it’s crazy. I feel bad.” Then it was very close to home, right? In my own house.

[So], yeah, she threw things. I had a glass vase, and she broke it too. She didn’t really throw it at me, but her anger was towards me. I thought it was. She smashed it in the kitchen, and I thought I got all the pieces, but I guess a piece got [missed]. [My daughter] told me later that there was a piece that fell in her bag. I didn’t know that. Well, she was slicing her legs with it. I was watching her and stuff like that and I didn’t realize but she had [the] piece in her hand. So, I could see all of a sudden, she had blood in her hand, so she was squeezing [it]. I felt like that was like the worst feeling. I was like, oh, I can’t believe I didn’t find that (piece of the vase) and I just felt so guilty. At this point, I’m like, I have to keep an eye on my kid 24/7, right?

I was dealing with having to be the first person to refeed her. So, I had told [my ex-husband], “She’s coming to you this weekend.” So, I just made him aware of what was going on. I was like, “We can’t leave her alone because she’s hurting herself.” I was concerned about suicide. That same night just before I was going to his place to talk to him. The [ED clinic nurse] got [my daughter’s] results. So [she] called me and said, “We have to admit your daughter.” I was just about to go [drop my daughter off at my ex-husband’s] and they said her heart rate was so low, we have to hospitalize her, or it could stop. So, we sat and just waited at his house with his girlfriend and [my daughter]. We just waited until they had a bed and then they admitted her and at [a nearby hospital]. They said, “Well she’s only here temporarily until spots open up [at a hospital with an ED unit].”
She ended up being transferred to (the hospital ED unit). It was almost three weeks I think (at the hospital ED unit). I stayed overnight the whole time [at the local hospital] and then when we transferred over (to a hospital with an ED unit), I stayed a couple of nights and then [my ex-husband] stayed a couple of nights. Not that it’s a competition with who stays more. We don’t [argue]. Basically, our philosophy is it’s not about us. Thank God we’re on the same page. We’re not trying to compete against the other one.

After [the ED unit discharge] we had to start just like before she went to the hospital; we had to start refeeding again. The whole food thing, and we had to basically be there. She was fighting, wouldn’t eat [anything]. That’s what ended up happening. She was still cutting and still like, it was just, oh, it was crazy trying to get her to eat and all that stuff. But I was to the point where I couldn’t sleep anymore because I was kind of like worried about getting up and what is she going to do? What happens if her heart stops? Because that’s what they had said too that if it’s so low, it could be so low it just stops.

It’s a good thing that there’s the support systems. I don’t know if I could of... you know… like if she wasn’t in the hospital… because that was kind of a saving grace for us. It was like, oh, we don’t have to force feed her. We’re her parents and you know, and her dad would say, “She’s my kryptonite.” She would get away with more with him. And I... and even to this day, I was the one that was feeding her more, and following what the dietician and [the ED clinic] was saying. I was the one that was, “You’re eating this.” I’m tougher on her. Where he was like, “Okay, she doesn’t….” Every time she’d be with him, because we do 50-50, she’d be lower in weight. Then she’d complain to me and say, “You feed me more than dad.” So, it was hard because then you start to get angry at them and you try not to take it out on them because he’s not doing it on purpose.

[The outpatient ED clinic] gave us a website or a conference group or something. They gave us a book, so we read about eating disorders. I just read bits and pieces like the philosophy behind it because of course as a parent you think, “What did I do wrong?” You still blame yourself. Cause as parents you always think what did you do to cause this? So, where does the responsibility lie? We thought maybe because we were separated maybe we caused it. That’s
what moms do right? How can you not see it? You blame yourself. You blame yourself for everything because you think you should have seen it. She’s your kid. How did you not know? I’ve actually gone through counseling myself to deal with all of that. You need the support. Yeah, it was challenging, because again it was like I had this little baby, toddler, that I had to feed and watch. Again, it was scary. Before, when she got admitted to the hospital she was cutting, she was being aggressive, all of that. And I was like, “Shit, this could happen again.” It scared me that I might have to be dealing with that again.

It was a lot of work because I’ve got to prep everything and make all of her meals and then you’ve got to... I was so concerned with making sure that I met the dietary needs that they wanted us to meet, right? So, it was stressful. A little bit of anxiety with having to be able to do everything and whether or not we could, right? And then tiring, because like, “Oh my god this is never going to be over.” I’d say probably more stress and anxiety. Just about everything. You feel responsible. Not being a good parent. Self-blame. That stuff kind of kicks in. Yeah, I would say that you get a little bit more... restless, I guess. Restless more. Yeah, just not comfortable really. I was bored. I wanted to go back to work, it’s driving me crazy. I just took it day by day, but then it felt like you know... And I kept saying I kind of wanted to go back to work. Emotionally you’re just kind of like, kind of done. Being at home and kind of frustrated with all that. Just having a 14-year-old that, you know... well she was going back to school half time but having to pick her up at lunch and it was a lot of driving.

I think expectation wise I would say [the ED clinic] were beyond... they met [my] expectations. I think it was really good. We just figured that they obviously were dealing with eating disorders before, so they were the experts. We didn’t challenge things that they did. [We] were just kind of following through with what they were doing at the hospital. So, kind of like being on top and supervising meals, making meals. It was hard. I thought it was like, “Oh I have a toddler again, I’m making them meals, and cooking everything.” Because, you know, it’s kind of nice when they get to be a certain age and they can, you know, help you cook dinner. I think we as parents are frustrated, feeding her every day, trying to make sure we got all the nutritional stuff and then fighting against her going “Really? Do I have to eat that much?” And her crying
and she still continued to cry and really when she first came home and everything. Again, that kind of slowly got better.

[The ED therapist] asks how things are going of course. It wasn’t really necessarily the “How are you doing?” kind of thing. How’s the family, how is she doing, how is the adjustment going, how is this situation? It wasn’t how personally you are doing. We even asked about maybe parent support groups and stuff like that, right? [The ED clinic] said that there was a little blog where you could go and they gave us that information and I know ’cause her dad read a little bit, which is people saying their frustrations and going through [it]. But there really wasn’t a support group here locally. I would say, if anything, just more parent group support where you can go and chat maybe.

I think I had a great support network. Like, at the gym and stuff like that, “how’s your daughter doing?” There’s lots of great ladies there [at the gym]. I’d just work out, that’s my structure. I just tell people that’s my pill. And people, friends, were always contacting to see how things were going. It’s not like I was a brand-new family in a new area not knowing people, which would be hard. I would just say maybe my work relationships because I kind of kept to myself. I really didn’t share too much information. Although people from work, they were contacting me regularly. “How are you doing? Good?” But I would just give them little bits of information. Not too much. It also is quite isolating. That’s part of your life and now suddenly you can’t talk to these people. It seems a little ... Yeah, well because if the information got back to the wrong people and things got ... my leave could be in jeopardy.

I thought we got away from this stage (of having to feed and supervise my daughter), so it was just more frustrating. I was not sleeping well for a little while. But it was short term. I’d say it was very stressful in the beginning. When she went into the hospital, her dad and I were relieved actually. I was relieved because now it’s like I don’t have to do this. I could just chill and be there and sleep with her in the hospital and just support her that way. And not really knowing how to support her either because with certain things you’re worried what you’re going to say. You didn’t want to spark anything. In terms of saying something like forcing her to eat. We had to be a little sensitive with what we said.
[Have any relationships changed, for better or worse or the same?] I think if anything, I’d say they get better. I think? Maybe my son, maybe he felt more [like he] didn’t get as much attention because we were focused on her, maybe? You know, kind of was angry with her a little bit more. I don’t know. I think we’ve got closer to her. Yeah, because you’re like “Oh, we have to pay more attention to her.” And it’s kind of nicer, we got a little bit more one-on-one time, right? Because I wasn’t working. I mean yeah, I guess her dad and I, [it] brought us a little closer in terms of communication. I don’t think anything got worse (in terms of relationships). I think you just kind of be more sympathetic to people. I want to be positive, but I still have to be cautious because she could have a downturn. I’m trying to be cautious with being too overconfident that it’s going well.

**Listening to Diane.** I’m always shocked when I hear how rapidly things move in the ED world, despite having worked in it for years. Once seeming normal to me, when I step out of my clinician role and get to see glimpses of what these hectic moments are like, I am met with a reality check. I can’t imagine the mix of chaos, worry, and surprise when Diane is told her daughter needs to go to an inpatient hospital immediately. When I hear Diane’s story, I am overwhelmed by how rapid their inpatient stay was, and how out of the blue it must have seemed. I just imagine her, her daughter, her ex, and ex’s girlfriend awaiting instructions about where they would be going, waiting in worry about their daughter’s heart.

As a result of her schedule, I met with Diane twice for one hour each time. The first time we met and began the interview she was tearful, and then apologized for being tearful when recounting her story of her daughter’s ED journey. I remember being taken aback by the sudden tears, and then when she apologized, I felt a sense of shame that my face must have showed surprise about how quickly the tears came on. I wondered if this was the first time Diane had
ever sat down and just spoken about her story. The tears were surprising to me given how she spoke with a soft, matter of fact confidence.

I remember being surprised hearing how positively she spoke about her ex, and how positive she was regarding the treatments she received, especially since I had met with mothers before who spoke about the challenges they met in treatment and their unsupportive partners. When Diane mentioned that her daughter’s weight would be down after spending time at her dad’s house, I remember feeling a wave of rage. I know how hard it is to put weight on, and hearing Diane speak of this with minimal frustration in her voice led me to be even more frustrated. It makes me think of how “off the hook” dads get in this treatment. Especially when Diane vocalized that she was trying hard to meet the dietary needs her daughter required for recovery, and that this led to increased stress for Diane. I felt angry that she would have to address the weight gain after her daughter spent time at her ex’s house.

Diane’s story also reminds me that while these women are trying to support their child through an ED, it is not always just an ED. Diane’s daughter was self-harming, and I just wondered how that additional issue affected Diane. She didn’t just need to watch her daughter’s food, but also her daughter’s safety. I remember being so perplexed when Diane said she blamed herself for not finding the piece of the vase that her daughter used to cut herself with. Why would she blame herself? How could she possibly know to check her daughter’s backpack for sharp objects? She never had to check her daughter’s bag before. This is a whole different kid that Diane now had to try to understand and parent, one that she had to try to figure out alone.
because there were no in-person supports available, with the exception of the ED team, who were more focused on ED behaviours and not checking in on her, per se.

I was surprised that Diane mentioned that relationships improved. This is not something I hear often. In fact, I often hear that parents remained anxious for their child and that creates a strain, or that other mental health challenges need to be addressed once weight restoration and symptoms have ceased and thus parents continue to have to be vigilant and rigid about boundaries. However, this surprise was met with something more familiar: caution for the future. I’m disappointed in myself that the “caution” Diane felt was more familiar to me than her expressing how relationships improved. When she says this, I am led to wonder what hope I instilled in parents given that my own belief was that they would have to remain cautious and vigilant forever. Did I discard or minimize the growth that came from this challenging experience?

**Yona**

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<tr>
<td>Employment &amp; Status:</td>
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<tr>
<td>Marital Status:</td>
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<td>Child’s diagnosis:</td>
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<tr>
<td>Duration with the ED:</td>
<td>~ 10 years (only knew of ED for 1 year)</td>
</tr>
<tr>
<td>Duration in treatment:</td>
<td>~ 1 year</td>
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You were a person long before you were a mom. I was left on my own a lot [as a kid] and I felt very isolated, I felt abandoned, I felt that there was no one looking out or protecting me. I felt like there was no one on my side, so I said when I have children, I will try to understand them, I’ll always try to look at it from their point of view.

I just feel so useless as a mother that I couldn’t protect [my child] because I didn’t know, and [my child] was assaulted in her young teens. I found out recently, that was the real trigger for a lot of this. I can support, I can listen, I can be kind and gentle, and I can drive her to her appointments and encourage her and make sure there’s decent food in the house all the time but I can’t, I can’t fix another person, so yeah, I’m, I feel helpless. I got laid off a year ago so I’ve stayed off so that I can work with [my child] for medical appointments and therapy. She’s only spoken out about asking for help less than a year ago, but the eating disorder has been for well over ten years. So, all though her teens, it’s been hidden.

There’s no real guidance. I’ve been given a little bit of literature, I sat in on a session with [my child] at the eating disorder counselling and they were suggestive of terms and words that I should and shouldn’t use, like “good food” and “bad food” is apparently something I shouldn’t say. You know I’m listening, but don’t put me down for it. I don’t think they mean to but they’re a little bit condescending, it’s like “Your daughter has an illness” and it’s like, “I know that. I’m the one that brings her there, I’m the one that’s taking a year and a half off work so that I can bring [my child] to all these things and try to get some help for [my child] and tries to get [my child] up and tolerates [my child’s] really grumpy moods where she’s grouchy,” ‘cause it’s not that that’s not hurtful, ‘cause it is, but I understand and I’m the one that’s lonely at home just by myself. I don’t ask other people’s opinions, sometimes I do but I always make my own decisions, I rely on my own sense of what’s right. I trust myself; I trust my instincts very deeply.

Most of the time I’m pretty happy, but dealing with the unhappiness of my daughter is a huge hole in my heart that I’m not completely joyous because [my child] can’t be, so it’s always, just the shackle on the leg that keeps you from being buoyant because someone you love is struggling so hard. I’m mostly awake and home by myself most of the time. I don’t like being by myself. I have friends. I like being with people, I like learning about them. I’m not always close
to them and sometimes it’s just light and I’m having fun, but my cup gets full. [There’s] a couple [of people] that I’m close to, but people always question everything. I play the cards with my daughter pretty close to my chest. I don’t open up too much about it because when I get negative feedback, I don’t want to rip my friends a new one. My best friend is 30 and he’s a man but we have so much in common with our difficulties and the difficulties we’ve had in life and he brings a different perspective. People that are my age tend to be more serious and they’re cut and dry in their little boxes. I do have friends my own age, I get different things from different friendships. I spend time with my husband and he’s a builder so we build things at home and make things, and sit on the couch as couch potatoes, but again, it’s a lonely time, it’s very lonely, and I don’t want to say, “poor me.” I’ve recently been diagnosed with type 2 diabetes, so I’ve had to change my whole eating structure for my own benefit. I can’t dwell on it and I can’t talk about it because it’s detrimental to [my child] so I’m on my own with this and again I’m not a weepy wimpy person but it’s still nice to be able to say, “Hey, I did this,” or “Hey, I lost 10 pounds,” and I can’t.

I do have to go back to work in the next few months. We have doctors’ appointments for the anxiety, the doctor for the eating disorder, and then therapy for eating disorders and some [therapy is in different cities]. And then my stuff is mixed in there too. Recently my car quit. I don’t have the money to buy a new car so someone lent me a car because [my child] can’t get on the bus. We’ve applied for ODSP [but] they don’t feel that [my child] has a disability. [My child] has no [insurance coverage] and it’s going to come to the point soon where we’re going to have to sell our house, because we pay for [my child’s] medical. We don’t have money for [private therapy]. I’m not whining, there are so many people that struggle, so I’m good, like I always say I’m fine, deep down there are lots of issues but compared to what other people are struggling with, I’m fine.

I have a feeling that [my child] would have been a statistic and taken her life at a young age and I’m so desperately afraid that that’s still going to happen. I can’t voice that to anybody because I can’t break down. I always have to be strong for my daughter, I am strong, I’m still human, and I’m just, I’m so afraid that if she doesn’t get better that she’s going to die and in that case there’s going to be somebody else that’s right beside her because there’s no way that I
would ever be able to carry on without my child, I love her so much, so much, so much that I would go with her… It’s emotion, it’s just emotion, and I always have a feeling that I can’t help. You push that (fear of losing a child by suicide) down, so far down because if you brought that to the forefront and you thought about [it] you would collapse and you wouldn’t be any use to your children at all, you wouldn’t be able to function if that was on the forefront. You know it’s there, but you also know that it’s in a vault and the vault is locked, and you don’t open it. It is far, far too painful for me. That might be different for others, but I suspect not. I imagine that a lot of people have never actually thought personally and in depth about [suicide], thinking that it couldn’t happen. A lot of people are dealing only with one disorder and maybe not, the two or the three, or four, we also have agoraphobia so there’s a lot of other things, but some people don’t think of the ultimate that it could happen, it is just like, “Oh well, that couldn’t happen.” Sure it can.

You feel like a horrible failure that you could not protect this person, and when people tell you that “Hey mom, you’re doing a great job and you are enough,” guess what? No, you’re not, nobody is, you’re not enough and it tears you down, it really tears you down. It’s just, it hurts to know that you couldn’t protect someone that you love more than yourself and then you want so desperately to help. It’s like okay, how can I fix this? Because that’s what moms do. They are the ones [that] make the phone calls, arrange for the counselling, call the doctor.

Having an adult child, I’m not allowed to know anything, I’m not allowed to take the calls from the doctor, but because [my child] has anxiety and depression so badly [my child] can’t make phone calls … and I’m not allowed in at the appointments, so I never know what’s going on. It’s taken like almost a year to go from the family doctor to nutritionist to eating disorder clinics, to psychiatrists for anxiety, for recommendations for this and it’s like, calls, after calls, after calls. Some people tell me one thing and some people tell me something else, and you know I’m not allowed to participate, it was only the once I was invited in for one of the eating disorder groups.

[Professionals] may have expectations for me, (but) I’m not doing, nor would I do anything because they expected it of me. You have to have your own common sense about things
and know that something maybe isn’t right. If you don’t find it useful, then you don’t (use it). A mom knows their child, they raise their child, they know them, or they should know them very well, like as an individual, obviously there’s lots of private things that you don’t know or maybe a child hasn’t shared with you, same as you wouldn’t share with your parents.

I don’t know if [my husband’s] a support. I’m mostly my own support. I get support in different ways from different people, so he’s there, he’s strong and steady in certain ways, like he’s there to make sure that the bills are paid. I don’t push because he’s tired and he’s working too but we’ll work together and build stuff and I find that very comforting. [My husband], he’s scared because he doesn’t know how to help, he’s scared about what’s going to happen to [our child] when he and I aren’t here anymore. Basically, it’s me that [my child] talks to because it’s not like [my child and my husband] don’t get along, he’s a very good, gentle dad, but they don’t talk a lot to each other so [my child] will tell me something and then I will tell [my husband].

I know I’m the only person that [my child] can actually take something out on. I’m the person that is closest, they have to push somebody or say something and if I can be that outlet, I will be. It’s not that it doesn’t hurt because sometimes it is very hurtful, but I try not to take it personally. I put on my Teflon suit. I will go in the other room and I’ll tear (cry) a little bit. I don’t have to share the dark places with anybody, but it builds up and something in there that just needs to bust out that I just need to go and let out and then I can deal with the dark stuff. I need to let it off somewhere, I mean years ago I would have been able to do it physically, I used to ski, I used to run, but when your body is breaking down and you don’t have that outlet anymore... I also do need the mental outlet, but yes, you don’t have to share the dark stuff, you just have to let the energy out somewhere, regularly and, you know, preferably not at home because you don’t need to burden your close family unit with that. They’ve got enough on their plate. You need to go do that somewhere else with a friend or something like that, who also needs to get their shit out.

I’ve always found it very difficult to ask for help. I would prefer to do it myself. I will never admit to somebody that I am vulnerable. Obviously I am. I am a human being. There’s only a handful of people, like two, that know when I’m vulnerable. If I ask for something once
and I’m pushed away or brushed off, I won’t ask for it again. It’s hard enough for me to ask once. I just don’t.

There’s always a chance, a great chance that [the eating disorder] isn’t going to get better, there is a chance that it will get better but it’s a very long process. It’s a slow process, so you don’t see progress and that’s hard that you don’t see progress. It’s going to be several years before [my child] gets back on track. I’m under time limit to get help for [my child] because I have to go back to work, I have no choice, and I won’t be available Monday to Friday to get [my child] to doctors’ appointments, so [my child] won’t be able to go. There’s nobody that’s going to employ me that is going to allow me to be off work whenever I need to be, you know, if I go back to work part time, I’m not going to make enough money, I’m going to have to sell my house, which would devastate [my child], so I don’t want to do that, I need to work. I’d like to be rich for a living. I don’t want to lose my job because then I need a paycheck. If I don’t have a paycheck, I can’t pay my mortgage and we don’t have a place to live. I hope I have enough energy to be effective and supportive during the whole thing and be there for a long time.

**Listening to Yona.** Yona’s story took me through emotions of energetic hopefulness, to utter hopelessness and despair, to total frustration. While most women in this research are mothers to teenagers, Yona is a mother to an adult child. I felt it was important to include her story because she is incredibly involved in her child’s life, despite her adult age. It serves as a reminder that when we only focus on age as an indicator for the involvement of mothers, we are creating an unspoken rule that you do not matter, or are not as needed, in your child’s life now that they are an adult. Yona is the protector and the one who has done an extraordinary amount of work, at great cost, to support her child. How is it that Yona is left being unsupported? Yona has such a strong drive to protect and support her child, yet she is left without support of her own, exacerbating this feeling of loneliness. This leaves me incredibly frustrated. I had great
urges to want to continue meeting with Yona to provide a safe outlet for her to express what was going on in her daily life.

Speaking to Yona really made me feel like I was talking person to person. When she spoke about her own history of abuse and being left alone a lot as a child, it reminded me that these are women with histories of their own, with their own challenging experiences that they’ve lived through. I felt Yona saw me, not as a professional, but as a genuinely curious person. She didn’t ask for my advice or thoughts, as many women did who must have known I had worked in this field. In my eyes, Yona just wanted to talk and share her story. I tried to cast aside my clinician-self (a hard thing to do), and just listen. The act of listening to Yona’s story totally exhausted me. This is a woman who is dealing with diabetes, her car just broke down, she just lost her job, she’s making and taking her child to numerous appointments, she’s the communicator between her husband and child, she’s the punching bag for her child, and on top of all this her family is struggling financially to the point where they may have to sell their home. And she minimizes these struggles with the knowledge that others have it worse than her. I’m exhausted hearing the numerous barriers that Yona has been faced with, and she faces these alone.

It was a terrifying privilege to hear Yona speak of the vault where she locks away her deepest fear, which she shared with me: the thought that her child could die by suicide. She speaks of this tremendous pain through tears that really pierced my heart, that she would die with her daughter. Immediately, my judgements come up from all that clinician training on attachment and enmeshment theories, and I shove them aside and get so frustrated with myself at
how automatic my judgements have become. In a moment of total vulnerability for Yona, my knee-jerk reaction is to judge this statement, instead of feeling it. Staying with Yona through this pain gives me a tiny glimpse of what it must be like for her to feel completely helpless while she witnesses her daughter’s struggle.

Yona is, in my eyes, this spunky, goes-to-the-beat-of-her-own-drum kind of woman. She was, for me, easy to chat with, was open with her experience and the challenges she is currently facing in her life. Participating in the creation of her story, I picture Yona as a martyr. Her daughter is an adult, and all the systems in place have given Yona the message that she doesn’t need to be here, doesn’t need to be as involved. Yet, at great physical, mental, and financial cost to herself, she continues to do all she can for her daughter. And she does this in silence, with little or no acknowledgement.

As I write this reflection, I can picture Yona saying, “It’s okay. It’s worth it for my child. It’s not about me,” and I want to scream that she deserves to be seen. She deserves to be seen for all the sacrifices, all the things she’s done to support her child. She deserves to be seen because right now I envision that the numerous players in her child’s care (the doctors, the therapists, and so on) have completely obliterated Yona from their minds. Yet she is the person that has not only brought her child to be seen by these professionals, but she is the very person that has kept this child alive.

**Gloria**

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If there is one thing I thought I understood and I thought I could protect my kids from, this is probably it. “Oh my God, I know what eating disorders are. I’ve [known several people] who had eating disorders. I know how they manifest. I know what the risk factors are,” and still here we are. [My daughter] had a previous diagnosis of anxiety and depression. We’ve had school refusal problems for at least five or six years, and a long history of struggling with emotional regulation going back to when she was a baby. She’s always been a kid with very, very strong, rapidly changing emotions. I also have a history of anxiety and depression and am struggling with perfectionism, although I never had an eating disorder or quite as many struggles with parents and struggles with emotional regulation as she does, maybe because it was a different time and I’d be completely terrified to mouth off at my mother.

I see it as part of a long narrative, and sometimes I have a lot of trouble disentangling her narrative about her eating disorder and my narrative about my own life, because one of the things that has for sure happened over this adventure is that all boundaries between her and I get blurred and reshaped, because she’s 17. She’s growing up. This is a time when she should be differentiating and separating. The emotional but also the logistical realities of the eating disorder meant that we went back to a toddler phase where I’m literally responsible for and measuring everything that comes in and everything that comes out.

She’d been in school about three days. She had just had her first day where she’d had to go to school all day and then have four hours of dance at night. She came home from that exhausted. I remember we were sitting in her bedroom. She said, “I can’t do it. I can’t do any of it.” I’m like, “What can’t you do?” “I can’t do school. I can’t do dance. I can’t do any of it, and I’ve been throwing up.” Basically, on that day, she stopped going to school and went down to
600 calories a day, and then very quickly thereafter to 300 calories a day. Knowing this kid and our history with other kinds of challenges, I was calling people the next day saying, “My daughter has an eating disorder.” People are like, “You don’t know that your daughter has an eating disorder.” I was like, “I do know.” The family doctor said, “Oh, teenagers sometimes stop eating, especially if they have anxiety. I think the eating disorder is secondary to the anxiety. We’ll treat the anxiety.” I was like, “Okay, but I’m pretty sure this is not going to go away.”

Four or five days after that, we were going to see her therapist, because I called her right away. So, we went to see the therapist, and we went from that therapist’s office to a form I admission at [a local hospital]. Because the therapist thought that she had suicidal ideation and that she had enough of a plan. Then the world fell apart.

We were at [a local general hospital] for eight days. I was like, “Okay, you’re telling me my kid’s suicidal. I want her here. I want her safe.” But I very quickly realized that I had lost all control of the situation, and there was no attention to food in that place, right? I’m like, “This kid has an eating disorder.” At that point, she just stopped eating. She fainted a few times, they had to give her an IV drip. But after eight days, I was like, “Send [my daughter] fucking anywhere, and I’ll just go with her.” So eventually they sent us to (another city’s child and adolescent unit) and they sent us home in less than 24 hours. “This kid’s fine.” I was like, “I think she has an eating disorder.” “She doesn’t have an eating disorder. She doesn’t meet the diagnostic criteria.” “What do you mean? This kid hasn’t eaten in three weeks. She’s lost 20 pounds now. She has not eaten.” [The hospital] ended up sending us a youth crisis worker from the [mental health agency]. It was the most valuable thing. I was talking to the youth crisis worker at [mental health agency], and she arranged for us to have an intake interview with the [agency’s] eating disorder team.

Then we’re in the all-day intake for the [local ED clinic], and they’re like, “Yeah, you have anorexia. Here’s your one-hour primer on family-based therapy. Go do it.” When she came home from the hospital, we tried really hard to do the FBT thing. It was very conflictual, and it was really hard. [My husband] would say we never really ever succeeded. I used to get really pissed off at him when he said that because who was getting meals and snacks into her? It was
Sometimes he’d be here for breakfast or at the end of the day, but I was the one. I was doing it. I was cooking the food. I never cooked so fucking much in my life until I had a kid who’s an anorexic.

She started to be monitored by the nurse practitioner. From the very first meeting [the nurse] was like, “I think this kid’s going to need to be hospitalized and really quickly.” Before we went to [the inpatient ED unit at the hospital], days [at home] were like, she was screaming, she was throwing things, we were trying our best to do this family-based therapy and put food in front of her. The amount that she would take was so little, so a lot of bargaining, the attempt to do excessive exercise… most days would look like screaming and crying, and “I won’t eat until 3:00 or 4:00 in the afternoon.” Then she’d relent and she’d eat a little bit and then that would be it, and we’d do the same thing the next day. Extreme is when all the bathroom doors and shower curtains [were removed]. So that wasn’t more than about two weeks after [the form 1] and we were in [the hospital’s ED unit] for the first time. I think 11 days that time.

Through all of that, I was [working]. I called my HR person. She said, “We’re putting you on medical leave.” This is why [my husband] and I are crying in parent counseling, because I end up getting just intensely angry with him. He was still going to work. He didn’t work much in December, but he’s still going to work, and I’m here all day. He did not take a leave. He took some flexibility. I think there’s a gendering to this that there’s often this pattern that moms do more of the physical work. We were pretty good about being equitable about that in advance of this crisis. But the emotional work has always been much more on me. This experience intensified everything. I was the one who stayed with her in the [ED unit at the] hospital. I was with her at [the local general hospital] for 24 hours. [My husband] would come for an hour or two a day and I’d come home and have a shower and eat something and go back. When she went to [the specialized ED hospital], I moved into [off site housing] and was there when she went back to [the inpatient ED unit] again for two and a half weeks. The emotional work has always been more me. He is the comic relief parent. He’s a fabulous parent. He’s a very involved father. He’s really involved with his kids, but he does not do emotional intensity. He never has.
I had so much guilt about being off work. It was like I have to do all the things, right? Because I’m here all day, I will do all the things. It was just flat out, “We can sit here all day, but I’m not going to eat anything, and I’m going to yell abuse at you.” So, we’re like, “Okay, you’re going up to your room. Okay, here we are with you in your room.” [My husband] and I would sit on her bed. I would sit with her for half an hour, and I’d offer the food, and she’d refuse it, and I’d go sit in the hallway for half an hour and I’d come back with the food again. I would just do that 10 or 12 or 14 times over.

[The ED therapist] was like, “It can’t go on like this. There’s too much conflict. [Your daughter] is not responding to this treatment (FBT).” Then we were back in the hospital and then the team there was like, “Okay, yeah. We always want you to try FBT first, but this is not working for you and your family.” Probably one of the things we should talk about is the weirdness of FBT and DBT. Making a switch that day, the hospital just said, “Okay, FBT doesn’t work for this kid. We’re going to try something different.” I’m like, “oh, you mean something really different? Maybe the DBT will give us some good skills.”

[DBT] worked better for her. It’s still me doing this endless amount of cooking and putting this food in front of her and still trying to encourage her to make better choices. And catering to her whims way too much. But she decides if she eats or she doesn’t eat. And she eats now. But [now it] is all about boundaries and separation and having control over your own self.

It’s like I’m responsible for all of the emotions. I can’t fucking do it anymore. Every piece of the guts inside of me was ripped out of my nostrils by this experience of the last eight months. And I am on the other side of it. I’m feeling like the way we used to do things is just not okay anymore. Because we are not out of this yet. We are still deeply in it. I am completely burnt out and I have trouble interacting with everybody around me. And now I’m a bitchy, overstressed parent and [my husband] is the fun parent. And I’m just getting more pissed off about it all the time. It’s things that maybe should have changed long ago. But now it has to, because I just can’t anymore. I feel like I’m barely hanging on by my fingertips off a cliff, even though [my daughter] is much better now. What I really need is for someone to be every day saying, “You’re doing a good job.” It’s just not the way [my husband] functions.
I have a very good friend who lives [in another city] and she just reached out to me continuously through all of this. But she has troubled teenagers of her own and her dad is in trouble. My best friend lives in [another city], but her husband has [health issues] and her daughter has [a seizure disorder]. Everybody is maxed.

After a bunch of sessions of sitting there saying, “I am falling apart,” that [my husband] gets that I am falling apart and that he has a role to play to put me back together. I kept everybody going and now I am falling apart. I have a lot of resentment about all of that. I mean, in some families it might be about which career is the leading career in the family. Which partner makes more money, which career is more or less interruptible. [My husband] and I earn about the same amount of money.

It was never a question about, “Oh, who will take work off? Of course [mom] will take work off. Who will go and stay with her in the hospital? Well, [mom] is already off work, so she’ll go and stay in the hospital.” So, each one of those decisions deepened the reality of me being the one who was the frontline worker. He’s okay when I say, “I need some support,” but I’m just so tired of being the frontline worker. I just can’t do it anymore. It’s highly gendered the way that it worked out, and in most of the families I know, because now I have friends who are moms of kids with eating disorders. It’s a very similar thing. At the eating disorder unit, you’ll see some dads come and go, but the moms are there. When your kid is in the [ED unit at the hospital], they want you to be supervising all the meals, because when you go home doing family-based therapy, that’s what you’re supposed to do. So, you’re in that room before 8:00 in the morning and you’re there until 7:00pm. [My husband] and [my other child] would try to come for a couple of hours every day or every other day. I would be like, “I just really need to get the hell out of here, but I haven’t seen [my other child] in days, and I haven’t seen [my husband] in days,” so what do I do? Do I stay here and try to actually be together with my family, or do I go and cry in my pillow at [hospital housing]?

This disease has taken all of our patterns, good and bad, and amplified them. Both between [my daughter] and I but also between [my husband] and I. I am emotions all over the place and a bit of a control freak and he’s laid-back and kind of lets it roll and that is how we
function. It becomes like, if I ask somebody to do it and they don’t do it, I will be like, “Then, fine. I will do it myself.” Because I do not have time to sit and ask you three times. I don’t have time and I can’t do it. But now we’ve reached this crisis point where I am broken, and it has been an incredibly stressful week for me. Not because it’s been so terribly bad with [my daughter]. There’s still bad stuff happening with her. She’s still purging pretty much every day. But because I have really tried hard to say, “I am not doing it. I am not doing it.” That is so much harder than doing it myself.

I got invited to contribute [to a work-related opportunity]. [It] was due two weeks ago. And it was a good opportunity. It’s a relatively modest project. I couldn’t even get the fricking [document] together. And after worrying about it for a week, I just had to say, “It’s not there right now.” And I just felt a loss all over again. My career has never gone where it might have because parenting around here has been super intense. I know I went through a lot of years trying to pretend I was both a full-time, at-home mom and a full-time, out-there worker. I just feel like I’m the best mother when my kids see me competent and functioning well at work. I feel like I’m the best role model for them and I know that they’re proud of me. But I know I can’t continue to function this way. I have to recover and we have to change this because this kid is going to be living with us for at least another two years and I absolutely 100% expect that we’re going down this hole again. I expect it to happen this summer.

[This has had] physical effects on my body. My body has hurt a lot. I’ve been in actual physical pain. I’m fighting to get my life back, but I am so deeply worn out emotionally and physically and I still don’t sleep unless I take sleeping pills. Right now, what we’re getting is me withdrawing from a lot of the parenting of [my daughter]. I am just… building a wall. It’s like, you can’t hurt me anymore, kid. She said some really hurtful things to me three or four weeks ago that I just have not gotten over. I’m trying to figure out how I build up my reserves again and that means I just don’t have time to do everything anymore. It’s not even about physical times, it’s emotional space. I don’t have emotional space to be in charge of all the things anymore. I just can’t do it. My feelings of guilt and exhaustion have just exploded, and I can’t do that anymore. I
I felt guilty about her getting sick and not being able to stop her from getting sick and now I feel guilty about not being able to get my shit together.

I just feel like I’ve been swallowing poison gas for eight months and now it’s starting to come out. And the people around me are not loving the coming out. They’re not loving being challenged by me or they’re not loving me being more withdrawn or they’re not loving me saying, “This has to change.” Because I’ve just been everybody’s sponge for so long.

In terms of what it was going to be like living it day to day: the fear of her hurting herself. The fear of her fainting, falling over. Fear around her physical state. Fear around her emotional state. I mean, we started with a suicidal ideation, so fear about that, which I don’t think has actually gone away at all. Actually, we were talking about that with our social worker on Friday and I ended up crying. I was like, “Yeah, I still think somebody’s going to die.” I’m not over it. I still think that could happen. And then the load on me was about unbearable. But once we were in it, I knew it was going to be me.

I think I’m weak. I think I indulged her too much along the way. [My other child] certainly thinks that and is quite angry about it. And increasingly, [my other child] knows exactly how to push her sister’s buttons. And she does it on purpose now. And [my other child] and I have had to have some discussions saying, “Don’t do that to your sister.” And she’ll say, “I’m tired of this. It’s my job. I’m going to push her buttons.” I’m like, “It was your job when you were three. And now you’re 14. And making your sister have a meltdown an hour before therapy is a really bad idea because nothing is going to get better in this family unless she goes to therapy.” She’s like, “I don’t care. She took my garlic bread.” And I was like, what the hell? [My kids] eat well, they get to do what they want. They’re probably spoiled in the material sense. They get all the support they need for school. I feel like we’ve done a lot for our kids and given a lot to our kids. But that I could let this happen to her has been really so much guilt, so much blame.

[Professionals are] telling me that my kid is really hard to deal with and really sick and I’ve done a pretty good job and I’ve kept her alive. She didn’t get to death’s door in that particular way and we’re going forward. Part of me is like, yay me. I did it. And part of me is
like, no, I’m just a fucking basket case and I’ve made this much worse than it needed to be. And there’s something bizarre going on in the relationship between [my daughter] and I. And I don’t feel like I know where to lay that down. She’s told me more than once that it’s my fault. She’s like, “Well, you know you talked about your weight too much, so it’s your fault.” [Now my daughter is] like, “Back off from my space.” And the rapidity with which this has happened is tough to take. She’ll have a day when she’s really vulnerable and she’ll pull me in close again. A lot of the stuff that’s getting me really upset. I’m having a hard time trying to figure out where I stand day to day. I’m having a really hard time processing my anger. I have a lot of anger. Anger towards her and anger towards [my husband].

Am I the best parent for this kid to have in this situation, or am I the worst parent, because if I was the best parent, she would not be in this situation? If I look back now, I’m like, kind of predictable that we were on this path. And it horrified me, but it didn’t exactly surprise me. I don’t even care how I’m seen [by other people] I just want to survive. I want to survive this. I want my kids to survive this. I’d like [my husband] and I to survive this, but frankly, that’s secondary. I never felt empowered by anything. I felt like maybe I kept her alive, but I never felt empowered by anything. I don’t know if I’ve ever been the mother I wanted to be. I mean, I think I’m a pretty good mother. I did until this. This made me feel like I suck.

**Listening to Gloria.** I met with Gloria twice; each interview was over an hour and a half in length. During the first session, the doors to the bathroom were put back on their hinges by workers. She had to remove the doors to prevent her daughter from locking herself in there and vomiting. The session that would have been our second interview was cancelled because Gloria told me that she had just been through a series of intense therapy sessions with her husband and child and was just in total emotional exhaustion. A part of me wanted to book another session, so I’d have a total of three, but I stopped myself from asking this of Gloria. The reality hit me that Gloria giving me her time was a total gift that she did not have to give, and I sometimes
wondered if she could afford to do it. These women are active in the boxing match, and I’m a reporter asking them what it’s like, while they’re being punched in the face. I think of my interviews, at times, as an inconvenience in these women’s lives, yet they still want to exert whatever efforts and energy they have in them to share their story.

Gloria’s story is not a typical one. Actually, none of these stories are “typical,” because they are focusing on the women rather than the children, but Gloria’s story really was an unfamiliar one to me. I felt that it was rare to experience a child just “switching” to restricting and telling their parents out loud that they were vomiting. Gloria’s story is very rapid, and it’s a whirlwind of intense emotions. I barely had a moment to catch my breath hearing her story. It’s so quick that thinking about it, and typing it, is even rapid in the moment for me.

The intensity of Gloria’s story has taken me a while to absorb. I wonder if she’s even had this opportunity to sit and absorb it, or if she’s purely just trying to function. While eliciting her story, I kept wanting to know more, more of what it was like, perhaps because Gloria was a great speaker and conveyed easily to me and with great emotion what realities she was facing. But despite my desire to hear for more from her, I got the sense that she was just so exhausted. I kept wanting more information, but by the end of our last meeting I saw that she just looked totally exhausted. I actually felt quite awful. I felt as though I had re-traumatized her by getting her to recounting her story.

Co-creating Gloria’s story is a struggle for me. She mentions how she has always been intensely close with her daughter, and I worry that writing that will lead to judging her story: another over-involved mother leading her child to an ED. This wasn’t the vibe I picked up on.
For Gloria, I had felt that this was a child that had always needed more emotionally, and that emotional role had to fall on her since that wasn’t her husband’s forte. This led me to be very angry. Surely he can learn the emotional piece! In the back of my brain, I hear these floating academic thoughts of “oh the bond of mother and child” and “the attachment and birth.” But I also feel like that is excusing her husband from the role he could and should be taking on. While Gloria talks about her worry that “someone is going to die,” a dark thought crosses my mind when I think that it is her. She is so burnt out, so done, and has been through such an intense experience, I start to wonder if she’ll collapse. She’s at a place now where the “poison gas” is leaking out, from inhaling it for so long, and no family members are appreciating this. It sounds as if her family just doesn’t understand the affect that this has had on her and are resentful that she wants to change the dynamics.

I found it very surprising when Gloria mentioned that this is hard because she knows her daughter so well. Many parents spoke of this “new child” that they had to learn about, but for Gloria that wasn’t the case. She knew exactly what was going to happen, and that sprung her into action. I picture it like I’m going to be in a boxing match with Floyd Mayweather: I can’t stop it from happening, but I know it’s going to be rough, and I have a very high chance of being obliterated. The only thing I can do is gear up to the best of my ability, knowing it still won’t be enough to survive. Add to this a partner, her husband, that could potentially support me through this, but I need more than pep-talks and small patch ups, I need him in the ring with me. That’s what I think about when I think of Gloria’s story. Alone in a boxing ring with the odds stacked against her.
What also challenged me in hearing Gloria’s story was when Gloria brought up that her kids are incredibly privileged (contrast this to Yona’s story). Her daughter is in an expensive, private, treatment program, they are connected with the ED program locally, both parents have very well-paying, secure, jobs, and Gloria also is on a paid work leave. However, it’s still not enough. Frustratingly, what privileges you have in life may sometimes still be not enough. It also makes me incredibly angry that it was Gloria that had to give up her career during this time. The one place where she felt she good was now no longer part of her life – at a time when feeling competent would be a welcome feeling.

When I last met with Gloria, she was in the process of trying to learn how to “step back” in order to have her husband “step up” in the care for their daughter. This made me incredibly anxious to hear. Gloria did mention how stepping back is hard, and I don’t blame her. She is already a pro when it comes to caring for her daughter, despite it totally burning her out. I feel so anxious to think of her husband stepping in: he has little experience and may not be as effective. It may eventually lead to Gloria having to re-enter the intensive care when her daughter is in a downward spiral. I acknowledge that this isn’t hopeful thinking, but it is what comes to mind. I can feel the sense of being stuck between a rock and a hard place: step back and potentially watch your daughter spiral downwards, and have to re-enter intensive care, or continue to stay as intensely involved at the cost of your own sanity. I’m sure the third option is to step back and watch your husband get a handle on this, and things are fine, but somehow that isn’t one that seems at all credible.
When Gloria said she needed someone to be there every day saying, “You’re doing a good job,” my heart broke. Probably because I know that’s what I need constantly—to feel like I’m on the right track, and that what I’m doing is what is expected of me, and that it’s “right” that I’m not screwing up everything. I know that feeling, not with the same intensity as she does, but wanting and waiting for the validation that you are doing a good job. It is something so simple, yet it is not there for her. It really hits me in my chest. I just want to tell her over and over that she’s doing a great job and that it’s okay to take a break.

Anna

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I feel like it took far too long for her to get treatment. And we were told this by [other professionals]. [My daughter] was basically left way too long. If it hadn’t gotten so entrenched, she would have had a better chance at a faster recovery. I really feel like [the pediatrician] missed the boat, [and] everybody’s careful not to come right out and say it, but you could tell from the other professionals. I guess you can’t be [up on the current knowledge] for everything, but this is one that pediatricians and family doctors need to catch a lot sooner. I’m pretty upset about that. I feel like I need to address that at some point (with that pediatrician), but I need to
wait ‘til I’m out of this. Maybe things like this will help raise awareness for doctors because it’s really upsetting, not that it could have been totally avoided, but that we might have had a better chance of getting it earlier.

I felt relieved when we got to [the inpatient ED unit]. I felt like the doctors were really good and specialized. They knew a lot about eating disorders, [but] it felt like they were hanging us out to dry at the end. I know it’s not the people, it’s the system that isn’t set up for that. They kept saying, “We’ll keep her as long as we can, but [she could be discharged] any day.” Then we literally had two hours to get out when they told us it was time to go, with no warning the day before or anything. I get why that happens. There are kids that are in more need, but that’s just not helpful when your family is in complete crisis [and] you’re not coping well anyway. All of a sudden there’s just so much to manage and then I have to go home and figure out: how am I going to feed her the right number of calories, and how am I going to make her eat it? It feels like it’s just so urgent. [My daughter] absolutely lost it a few times and was talking about running away and was screaming and saying she wanted to go back to the hospital. I’ve never had to deal with anybody like that before. Maybe you can’t be prepared for that, but you just don’t know what to do when somebody has completely lost it and then they say, “Well, you can always take her to the emergency room.” It feels so difficult and hopeless, because everybody’s saying, “Oh, no, sorry, we can’t help you with that. You’re just going to have to go home and keep feeding her. Bring her back if she stops eating.”

I think one of the worst things for me was that a social worker there told us basically that [my daughter] wasn’t ready to go home and she probably wasn’t going to get better if she went home, but that she was going to be discharged. It’s like they dropped this huge bomb on us, like, “Okay, she’s really not getting better. She’s so rigid and so stuck in this that we don’t think that she’s going to continue to improve once she goes home, but we can’t keep her any longer.” That was awful. They told me one day they were going to discharge her after three and a half weeks and I lost it. I was just crying and then nobody came to talk to me for quite a while, and I’m sure they were busy, but it kind of felt like, “Okay, this crazy mother crying in the room, we don’t want to talk to her.” Anyway, they decided that it would make sense to keep her for longer, but I
don’t know if that’s just ‘cause I had a meltdown. I keep thinking, “Okay, this is the worst day of my life.”’ Then a week later you think, “No, actually this is the worst day of my life.” You just keep thinking it cannot get worse than this and then it does. Obviously, it can get worse than that, but in terms of anything I’ve experienced… it’s truly horrible. I remember that at the hospital and the first few months home thinking, like, “I have got to get out of here.” And then thinking, “And I can’t.” One of the most awful things about it is that it changes your child’s personality and makes them horrible to deal with, and that’s just really hard when you’re trying so hard to help and do what you’re supposed to do.

It’s a bit condescending that the experts know, and the parents don’t. I don’t believe that’s how most of those people really feel, but I think just listening to what parents have to say is good. And they always sort of do, but maybe not really giving it the weight that it needs to be given. Or, it seems to take a long time to get somebody to actually problem solve with you and to really try and figure out where you’re coming from. They’ve got a certain perspective that they’re coming from, but as the parent side of it it’s pretty hard to feel like people are listening or caring. Maybe I’m just imagining, but in my mind, I’m thinking they’re saying, “Yeah, yeah, yeah, mom. Whatever. Yeah, we hear that all the time.” It feels crappy to have to be treated like, “Oh, yeah. We see this all the time with parents.” That just feels not very good.

The transition home is so very difficult. They say, “We’ve given you all these strategies,” but it’s not enough. At least with what we went through. It’s more just like, “Oh, you’ve seen the nurses work with her.” Yeah, I saw them but she’s nice to them. She’s polite to them. [My child] has never been violent, she doesn’t throw food, [but] she’s verbally violent. Things happen very differently than they do at home when you really have nobody. You have to wait a few days or weeks to go talk to somebody again and you’ve got this problem you don’t know how to solve. It feels like that’s the level of support you need is somebody with you. Family-based therapy isn’t about what it sounds like. It’s like family-administered therapy. It’s teaching parents to be there, or making sure parents are on track with being the caregivers. It’s about how to get the family to get the kid to eat. It’s not about the family, really.
I guess we’re lucky we have the resources to get help separately. It’s been very difficult, partly because I think neither [my husband or I] are in a great place mentally or emotionally. [We] have a lot of differences about how to deal with her behavior when she’s being horrible. It got to a boiling point and we actually talked about splitting up, but we’ve worked through it and we’re getting some counseling. Neither of us wants to split up, and we both recognize that the only thing we’re fighting about is her. [My daughter and my husband’s] fighting causes me a lot of anxiety. They’re both yellers and I’m not like that, so having that level of conflict going on around me is very stressful for me. I felt like nobody really was grasping what was happening. They say, “Oh, you need to present a united front.” Okay, but nobody actually knows what’s happening. He actually left for about a week … with my blessing because things had gotten so bad. I remember talking to the [ED therapist] and she seemed shocked that things had gotten so bad. I was saying, “He’s yelling at her and he’s berating her.” And she said, “Oh, no, no. He can’t be doing that.” “I know, that’s what I keep telling you!” They kind of have a box that the anorexic kid fits into and how the mother acts. I’m sure this isn’t an uncommon family dynamic, to have dad being more forceful than mom and mom and dad disagreeing. I’m sure everybody hears it all the time, but this has been a huge piece of what’s going on for us and we really have had to seek help separately to get anything addressed with that. I’m seeing a psychologist, [my husband] is seeing a counselor, we’re getting couples counseling.

Sometimes I can think, “Okay, you know what? This is her and she’s sick.” But [I have] a lot of guilt about it. She’s suffering so much already, and when I’m the person that’s directly making her suffer … it just feels terrible. It doesn’t feel like what a mother is supposed to do. She’s beyond persistent, so if she wants something, she’s just after me and bugging me, and so I’ve started telling her that “I’m done. I’m ignoring you now.” We’ve gotten to the point where I’ve had to lock myself in the bathroom or bedroom and she’s pounding on the door telling me not to ignore her and I shouldn’t be treating her like this. With me, she’ll fight about food or calories or the choices. With my husband they have a pretty rocky relationship anyway, so he doesn’t do much of the food stuff with her.
What I’ve learned through all this is you basically have to use a really strict behavioral model to get them to eat, and that’s not me at all. One of the really hardest things for me is learning how to be really tough. It felt like child abuse. [ED therapists] kept trying to convince me that it’s not, you’re preventing her from hurting herself, but it just felt so wrong. Basically, anything she had or wanted we were going to take it away. It’s awful.

My husband is on a mental health leave, at least in part because of this, so that’s been hard. I think my relationship with my daughter has changed a lot. [I feel] like a jailer. There was a stretch where she was really horrible to be with, so everything’s just been complete chaos. I mean, it’s not as much now, but it’s just so time consuming. There’s no way I could have worked during a lot of that time because shopping and preparing meals and sitting through meals takes up [time]. It’s like having an infant, except the infant’s hurling abuse at you. For me, because I have an anxiety disorder and my own mental health is not perfect, I feel like maybe somebody who didn’t have those mental health issues could do a better job of not taking it so personally or not being so affected by it. Right now, until she’s well, there’s nothing that’s going to make her happy. Everything I do is a battle, but if I don’t do it then she gets sicker. The amount of conflict to me is just so hard to deal with, but I can’t stop. So, I think I just really feel stuck, like I’m in an impossible situation a lot of the time.

[Child] has continually told us family-based therapy won’t work for her because our family is so terrible and messed up. I think a lot because of her relationship with her dad. I mean, I think it is working because she’s eating now. At least to some extent it’s working. The other thing they talked a lot about was how, for parents, you need to treat it like you would any other serious physical illness. Like if your child had cancer, you would take a leave of absence and you would be there with them every step of the way, and that with anorexia, you have to do that too, and that people don’t always recognize that, how important it is to just ditch everything else in your life and do what you need to do for your child. So, I think that was good. Hard but good, because you know what you need to do, so you don’t have to feel guilty.

[I’ve] talked about mealtimes and just the stress, and marriage and siblings, but even basic self-care like eating properly and exercising. In addition to not being able to go out and
socialize, you’re not really taking care of yourself particularly well. You just don’t have time to
and it’s not a priority. [My happiness is] just not a priority right now. It can’t be a priority right
now. I can’t do a lot of things that I want to do. This stuff’s hard to talk about. Our marriage has
really been struggling and I can’t go out quite often. I think it’s sort of keeping my head above
water as much as I can and just hoping that it’s going to ease up. It is better than it was. I do have
a bit more freedom than I did. I’ve just started back [to work] one day a week [and] I’m really
happy to be at work when I’m there. I work for a private company, so I’ve just had no income,
which stinks. My family is always asking if there’s anything they can do. My mom’s supporting
us financially right now. I’ve gone out for dinner with friends occasionally. There’s not really
anything anybody can do. I have a good friend who lives next door to us and she and her
husband both helped us a lot.

I think [my family and friends] mostly feel really sorry for me. I think the whole thing’s
just been kind of shocking for them too. I get a lot of support for me personally from them,
which is nice. But I can’t always tell them what I’m feeling because sometimes it just seems like
a bit much for them to actually hear that, ‘cause sometimes I’m just so angry with [my daughter].
I went through a point where I was having suicidal thoughts and [my husband] knows, but I
haven’t told anybody else ’cause then I’m just sort of loading it onto them and there’s nothing
they can do about it. People don’t know what to say and then they just feel awful too. I know my
mom and my sister are so worried about me already that I don’t want to tell them that because
there’s nothing they can do and then they just worry more. Everybody’s got their own stuff, so
they don’t need more to worry about.

I think that [ED professionals] think I’m too soft, that [my daughter] has been running the
show for a while and that I’m really struggling, which is very true. I’ve been doing it as much as
I can, but I think they know I have struggled with it quite a bit. I think that’s why I found my
psychologist so helpful, because she can frame it a different way and just say, “You know what?
I think you’re reacting totally normally given what the situation is.” I always worry about what
they’re thinking of me, and are they thinking that I’m making it worse or are they thinking I’m
not doing a good job? With all the food stuff I feel like I’ve done a good job, and they feel like
I’ve done a good job. It’s the behavior stuff that’s harder. The professionals tend to come back with, “Yup, that’s fairly typical of eating disorders. We see this all the time.”

We have [an autoimmune issue] in our family. When we got to [the ED hospital] they brought in a [specialist] to talk to us and convince us [that she doesn’t have the diagnosis] and by acting like we’re restricting her food even more. I kept trying to think, “Okay, these people know. I don’t want to be crazy.” That’s how you feel, like a crazy mom. Since we’ve been home, she got a really bad [reaction] and I said to her, “You know what? Let’s just try this (food-group elimination) for a few weeks, see what happens.” [Symptoms] went away. I thought, “Okay, I’m not doing this anymore. They can tell me my child doesn’t have this, but I don’t really care.” I work in healthcare and I understand that sometimes parents are not seeing things. I totally get it, but the guilt of not doing what they say is hard.

[My life is] on hold right now and I’m trying to get little bits of it back. I’d like it if [my husband] and I could be together and not have this constant source of conflict. I do think that when [my daughter] is not at home anymore things will calm down quite a bit because she is the main source of our conflict. I’d like to be able to use my kitchen and not have somebody challenging me all the time. I can’t say that I feel exactly the same way about [my daughter] now. I love her just as much, but I’m angry at her. I know it’s not her fault, and she certainly didn’t ask for this, but it’s not how you’re supposed to feel. I guess the perfect mother would be supportive, no matter what. I guess they wouldn’t be human then. It’s hard to go out and have fun and forget about it when your child is really suffering. Part of the guilt is [that] I’m not doing absolutely everything that I can all the time ‘cause I just can’t. I feel a little guilty about that, and then I’m just sort of feeling guilty [that] there are a lot of negative feelings about her and about all of this.

I just keep hoping it’ll get better and better. I don’t know what will happen [if it gets worse again]. I can’t even think about that because I think our family will completely self-destruct if it gets worse again. We actually have positive interactions with her some of the time, so it’s a lot easier to be in your house. When you’re trapped in your house with somebody who hates you and is furious with you all the time, it’s very stressful. Now we’re all able to get out a
little bit more. I guess in my mind I sort of think, “I have to do this while she’s a child” and not just because when she turns 18 I’ll be like, “See you.” But if she doesn’t have to listen to me and she can do what she wants, she will. Then maybe I just need to disconnect at that point because I will drive myself crazy trying to help her and she won’t let me. I may just have to accept that. I try not to think too much about that, but there’s a point, right? You can’t do this forever.

[The glimmers of hope are] gifts only because things were so awful. I have heard people say that when they work through this kind of thing as a family that their family gets closer. And I don’t think we’re there yet. I just want to get back to normal and be able to work and do the things I like to do. Just seeing friends. We foster puppies through a rescue […] so that reduces stress for all of us. It’s something positive to focus on. [I’d like to ] just see friends [and] I would probably [like] to spend a lot more time doing [the dog fostering] and volunteering.

[There are] gifts in terms of support from our close friends and family. To know how much people care about you and try to help you is a gift. [I’m surprised that] I made it through this far, but also just how bad things can get. ‘Cause it’s pretty bad. [I hope that my husband] and I make it through this and stay together, and that we will actually be a family that can connect, and like each other, and talk to each other, and stay in touch. I do worry about losing her, so I hope we don’t lose her.

**Listening to Anna.** I feel trapped hearing Anna’s story, and thus anxious. I feel the anxiety and stress radiating from her into me. There is a familiar feeling I hear from Anna’s story when she talks about everyone experiencing the same issue (the ED), but everyone sounds so disjointed and fragmented. There’s an intense unity on the surface, but an isolation and deep sadness in each individual family member. Literally everyone in this household (minus the older child) is in the home, struggling, as a result of the ED, but all are fragmented. It’s similar to what happened in my family when my brother died. It’s an odd feeling and I understand the challenges
of putting it into words. There are people around, it’s loud and intense, yet also very lonely. Her story reminds me of this experience in my life.

There are a lot of pieces that ignite rage within me, from her husband being unable to support her, to a late diagnosis from the pediatrician, to service providers being unhelpful, to the absolute decaying mental state from festering in this intense, abusive situation for a long time. One of the biggest things that infuriated me was Anna telling me how her daughter was discharged from the hospital and being told that her daughter wouldn’t get better at home. I’m just angry and perplexed about why that statement would be made to Anna. What was the intention behind saying that? Was the idea to “motivate” Anna to do more (although I have no idea what more she could do)? Clinicians cannot predict the future, and I’m angry that this message of certain, impending failure was suggested to Anna.

This story reminds me that these women are well aware that they are being assessed and interpreted. While she never may know what the clinicians really think of her, my guess would be that she is pretty damn close to correct when she tells me how she thinks service providers view her as being crazy. I felt shame because I remember meeting with mothers who did not feel the way their child was eating (vegan, low carb, low fat) was a particular issue, or that exercise was helpful, and it became a power struggle of who knows best. I admit that when parents didn’t do what I had recommended, I felt incredibly frustrated. I viewed them as choosing to engage in “treatment interfering behaviours.” When Anna spoke of breaking down, crying, at the hospital when they were going to send her daughter home, one part of me thought, “squeaky wheel gets the grease, good job! Do whatever you can to show you need more support.” Of course, another
side of me is angry that crumbling down in total fear was the only way to get her daughter to remain in hospital. The cost of getting what her daughter needed was Anna sacrificing her own image to the hospital staff.

Hearing Anna’s story really reveals all the mistakes I made, and all the judgements I’m guilty of making towards mothers. When Anna said how she tried to convey to clinicians what was going on in her home, it really opened my eyes to the fact that we may never truly understand what is happening in these homes. It’s an additional stressor and pressure to have to try to get people to understand what’s going on in their home. When I hear what was going on in Anna’s home, and the high level of distress, I feel completely hopeless. Her husband’s own struggles to support his daughter just put more work and strain on Anna.

When Anna told me about the suicidal thoughts she had, I was immediately overcome with emotion. I recall tearing up in the interview, and then I remember not being sure what to do with my facial expression. One part of me felt privileged that Anna shared that reality with me, because deep down I always felt that mothers were somewhat immune to suicide because their child is a “protective factor” – they don’t want to put their child through that. It was a bit of a reality check to hear the depths of her pain. Another part of me felt guilty for all the women I had pushed to “keep going” fighting the ED for their child, alone, without support, at all costs, never really feeling that suicide was actually an imminent thought. I knew that they were struggling, and that anxiety in these women was high, but I never really thought suicidal ideation would actually be in their minds. Maybe it’s that thought that many have: when a mother dies by suicide, those thoughts of “how selfish was she to do that to her children” comes up.
Co-creating Anna’s story has been an interesting process. Anna attended my interviews despite having a significant head injury that prevented her from being able to drive, despite her limited time, her own medical issues, and the stress she was under. She still wanted to dedicate time to share her story. Additionally, she spoke in what I took to be a soft voice, and thoughtfully selected her words when speaking with me. I don’t want to portray her as weak. As she said, she’s surprised she has made it this far, and is surprised how bad things could get, yet she survived it, though at great cost to her own well-being. I actually hate what I just wrote. I don’t know how to conclude my thoughts about Anna. I don’t want to end on a sad note, but I do feel sad. I want to be proud of her having survived this, but I feel immense sadness that this has been her reality. Anna had her own therapist, her husband had his own therapist, they did couples work, and on top of this they are doing FBT for the ED. They had family that were supportive, financially and emotionally, but it still wasn’t enough. Or maybe it was enough, since she made it through. I feel melancholic as I end this reflection.

**Listening to 10 Women**

I have read these 10 stories numerous times, and every time I read them, I end feeling overwhelmed and exhausted. When I read through these stories, I’m reminded that none of these women *have* to take on this role. They could just say they can’t do the work and refuse to undertake the recommended treatment. Of course, by doing so they would be stigmatized for failing to provide treatment for their child – although, in reading these ten stories, these women are still feeling like they have failed, or are failing.
It’s never enough. It’s perplexing to me that this illness demands so much of mothers. Reading through these women’s stories, I am struck by how much the eating disorder impacts their lives, and I think as a clinician I forgot this. Simple grocery shopping trips are all-out tests in nutrition to find the most calories. Preparing meals requires not only the expert knowledge of a dietician to refeed their child but also extreme patience and perseverance. I try to imagine that every four hours (every mealtime) there will be a verbal, and sometimes physical battle. During the times in-between meals, these women’s minds are occupied with counting the calories consumed, preparing meals and snacks, reading research on eating disorders, making decisions around meals, and getting prepared for the next meal-battle. These women put on an armor of numbness in order to prepare. And this was a battle they took on alone.

Of course, these are individual stories, each with their own uniqueness. These women had different strengths, different areas in which they struggle, different privileges in life, different histories, and different relationships. Some took leaves from their jobs, others didn’t. Some had therapists of their own, some didn’t. It is important that these stories are presented so that the reader can see the uniqueness of each woman’s story. Yet within their unique, individual stories, there are storylines that thread and connect these women’s experience. The tension concerning self-preservation, but also needing to act immediately, was evident for these women. They highlighted the challenges that their role required of them, both physically and mentally, while also needing to put their needs aside and remaining present and available 24/7 for their child.

The next chapter will highlight the common storylines connecting women’s experiences to each other that I feel are important. I have grouped these storylines into broad categories. I
will take these individual stories that I have co-constructed and apply an analytic approach. I will remark on possible future directions for scholarship in this area.
Chapter Six:
It Is an Overwhelming Challenge to Live with Daily Eating Disorder Demands

Presented first, this most important storyline, included in all 10 accounts, is the primary one. If we do not understand what these women face on a daily and continuing basis, we will not be able to understand how to support them through their experience.

I think many professionals who work in the ED field feel that they understand how these women survive their day-to-day experience. I thought I knew, but what really became apparent to me through these interviews was how much their role demanded, and the psychological costs of those demands. It seems so obvious that these women would be completely exhausted – so obvious, in fact, that writing this section presented me with a challenge. What more do I have to say or elaborate on? But that’s just the issue. This storyline is so imperative precisely because it is so obvious that we fail to give it sufficient consideration. We focus so much on the child’s recovery that we forget that these women are in challenging and even traumatizing situations. Being a clinician myself, I had often thought that the faster we get the child out of their ED the better. But rarely did I think of the cost that this treatment emphasis would have on the person responsible for getting their child out of the ED, namely, the mother. These stories indicate the great impact on these women’s lives of the roles they attempt to fulfil. I believe their daily experiences need to be clearly laid out for the reader in order to truly understand what these women are experiencing.

This storyline plays out in multiple ways, over multiple time periods, and in multiple situations for these women. Some of the women are just beginning this ED journey. They are on a learning curve to acquire all the knowledge they can about EDs and adapting to a new style of
Some women have been on this journey for an extended period of time and are exhausted but carrying on. All of these women have made incredible sacrifices in their daily lives. Some women have their brain hijacked all day by thoughts of the ED and the responsibility they feel concerning its onset. This ongoing thinking and planning takes a toll and leads to shame, guilt, and grief.

The powerful emotions that these women feel are further exacerbated and amplified by the isolation they experience. These women are alone in their planning, in their managing of behaviours, and in their pain. This reality was captured not only in their written stories, but also in the curiosity they expressed about each other, a curiosity that revealed itself when the audio recorder was turned off. These women were interested in who else I was interviewing, whether their experiences were similar, what patterns had been seen, and what other women in similar situations were saying. While some women had partners in their lives, the role that significant others played in supporting them was, generally speaking, not helpful. Women struggled to reach out for support to extended family for fear of judgement or not wanting to burden other family members with their challenges. Friends were not always helpful either because they did not understand what these women were experiencing. Additionally, it was not even realistic or practicable for these women to reach out, given the daily demands that they were expected to respond to. The time to meet with others was simply not available.

For these women, their own distress and personal wellbeing was superseded by their child’s. This sense of diminished status was demonstrated by their own hesitancy in making future plans, and the seeming impossibility of thinking of the future. During my interviews, it
was even a challenge to have these women speak about themselves. Such diffidence was perhaps due to the unfamiliarity of speaking about the impact of the EDs on them and their roles, since the ED is always discussed in relation to their child and what they are doing for them, and rarely, if ever, are they asked how all this “doing” is affecting them, their lives, and their wellbeing. At the end of my interviews, many of the women spoke about how it felt to go through this interview process. Rather than talk about skills, or techniques they needed to learn, or problem-solving challenging behaviours that arose or meal ideas, talking about themselves was a new experience. They experienced a space to allow themselves to just speak about their experience without feedback concerning how they were doing in their role.

**Life Revolves Around Food:** “I never cooked so fucking much in my life until I had a kid who’s an anorexic” (Gloria)

When we think of EDs, we obviously think of food and the need to get food into the person with the illness. In fact, many women talk about the frustration they experience with extended family members and friends who do not understand that it is not as simple as to ‘just make them eat.’ For example, as Adrienne tells her story, she speaks of waking up at 5:30 am to make her daughter breakfast, and then, while at work, counting calories to ensure that her daughter has had enough to eat and planning the evening meals. These women are cooking in ways that are not familiar to them: thinking of how to add more calories to meals, substituting ingredients for higher-calorie ones. Adrienne spoke about going grocery shopping *daily* in order to have items for the meals she needed to prepare for her daughter. The action of shopping and preparing meals adds stress to days that are already a challenge. And beyond the time required to
shop and prepare is the daily mental effort of thinking and planning these meals. Recall Anna, who said: “How am I going to feed her the right number of calories, and how am I going to make her eat it? It feels like it’s just so urgent.”

Once meals are prepared, the second phase of supporting their child through the meal commences. I think of Cordelia, who spoke of snacks going on for 45 minutes, and some days where the meal would not be completed at all. I think of Gloria who spoke of bringing her food up to her daughter’s room, frequently re-heating it when the meal was refused time and time again. The effort that has gone into buying and preparing a meal is often met with total refusal, frustration, and even violence from their child. These women have spent hours shopping for high-calorie items, coming home to prepare a meal with a focus on nutrition, only to be met with the extended time required to get their child to eat. This meal support comes in many forms: being present and sitting beside their child; saying encouraging words with each bite, or remaining silent, just being present at the table with their child; or repeatedly re-heating their food and being persistent, maintaining that the meal is non-negotiable – food is medicine.

Learning a New Way to Parent: “It changes your child’s personality and makes them horrible to deal with, and that’s just really hard when you’re trying so hard to help and do what you’re supposed to do” (Anna).

Typically, these women are supporting their children through three meals and three snacks every day. I try to imagine waking up at 5:30 am to prepare a meal with great care, then planning a snack for 10:30 am, then a lunch for 12:30 pm, then an afternoon snack at 3:30 pm, then dinner at 6:30 pm and then a final evening snack at 9:00 pm, all with incredible
thoughtfulness. To quote Cara: “You get so focused on food prepping and so forth. It’s constantly like, okay, what’s, what’s the next meal?’”

Adding to the stress of the constant planning and prepping of meals is the behaviour of the child with the eating disorder. The child becomes unfamiliar. Some women spoke about feeling like they had a toddler again, but one with more strength and a harsher vocabulary! As Anna had said, “It’s like having an infant, except the infant’s hurling abuse at you.” For others, it was as if their child was possessed by some external force, as if a devil had taken over their child’s brain. Regardless of how they interpreted the change in their child, what was clear is that they were now learning how to manage these new behaviours and extreme emotions.

During mealtimes, women spoke about the challenges of having to change their previous parenting style. Anna mentions that it is “a strict behavioural model to get them to eat,” and she had felt that that was one of the most challenging aspects of living with the eating disorder. For her, the change in parenting style in order to manage the ED “felt like child abuse.” For other women, key moments happened during the fallout after mealtimes. That is when their child’s emotions were most intense, leading to physical violence directed at them. As Yona had said, “I know I’m the only person that [my child] can actually take something out on.” It is important to highlight the violence that accompanies eating disorders. The women spoke of the great shame they felt that violence was taking place in their home. For some, such violence even led to the involvement of Family and Children’s Services. This is the reality that these women were frequently experiencing. While physical violence was perhaps not taking place every day, the emotional and verbal violence was often present, in varying degrees, throughout these women’s
days. And the abuse was always directed at them. Many women also spoke of the challenges presented by the roller coaster experience of a typical week, and how the unpredictability of the moods and behaviours that might surface were just as difficult for them to manage. These women were constantly on high alert for what could be coming through the door, or what emotions could surface after a meal. The state of being on high alert and constantly vigilant takes its psychological and emotional toll on these women.

**The ED Encompasses My Whole Life:** “[I] live and breathe and poop and eat [ED], everything was ED. I had nothing else in me but ED” (Adrienne).

Daily life is grocery shopping, preparing meals, being present and supportive during meals, and learning new ways to parent and care for their child through highly emotional situations. Living with an ED, and caring for a child with an ED, means always thinking about the disorder and its demands. Besides getting groceries and preparing meals, there is the supervising and monitoring of meals, as well as being the person that absorbs the violence. In addition to that is the driving to appointments, the advocating for children who can’t advocate for themselves, and the ongoing mental effort invested in immediate plans.

I think of Yona and Mila who were advocating for their children in different ways. Yona was making the appointments for her adult child, and then driving her to those appointments. In addition, she was the one seeking out support for her child, since her child was too anxious to do it for herself. Mila was calling the hospital her child was in and advocating for better communication with parents and better services for her child. For some women, even adult children, or children in intensive care facilities, require the continuous day-to-day support.
What struck me as well, when I asked about their future plans and goals, was that many struggled to answer. “I can’t even begin to look at [the future] until [my daughter] is well settled” (Cara). It makes sense that women like Cara have to place their daily focus on the ED, especially when their daughter’s “success and failure are 100% on me.” These women are the ones at home with their children, since they are typically the ones that have taken a leave from work; they are the ones that are preparing the meals, arranging and attending the appointments, and they are the ones that take on the emotional labor. And they do all of this on their own, every day. Their tasks are all consuming.

**Experiencing Loss:** “I am grieving a lot of things” (Cordelia)

In the sections mentioned above, a lot of the discussion revolves around the mother’s responsibility to the child and the ED: shopping, planning, cooking, monitoring, going to appointments, and taking on the emotional labor. While this reality was very present in our interviews, and it was challenging to have women take space to talk about themselves, it is important to mention the very much overlooked aspects that put additional pressure on these women and contribute to their experience of grief, shame, and guilt.

Some of the women who took part in these interviews continued to work full time, some reduced their hours, others decided not to seek out other employment at this current moment, and several took a leave from work altogether. Adrienne, who continued to work, added ED responsibilities to her workday, counting the calories her child had consumed so far in the day and planning the remainder of the day. Gloria, who took time off, was left questioning why she was the one who had to take the leave, given that she and her husband had similar incomes.
Gloria also mentioned that she had “so much guilt” about being off of work, and that her “career had never gone where it might have because parenting around here has been super intense.”

There is a grieving for the loss of work, the place where these women felt competent. Some women continued to work in the area in which they felt competent, but continued to feel that they were failing their children in the ED world. Those who took time off completely felt even more acutely the pressure of treatment success as being determined by them. “It becomes 100% of my responsibility, her success, or failure is 100% on me. I mean, her success and failure are 100% on me, I’m quite sure [my husband] thinks that too” (Cara).

Circumstances and realities also took a toll on relationships with partners. Women who were married spoke about the tension that the ED brought into their marriage: “It brings up the shit in your marriage, and then makes it shittier” (Adrienne). Women stressed having no time to work on their relationships, either because the time spent caring for their child left them completely exhausted, or because of resentment towards their partners for being unable to better support them and their child. Those who were not married did speak about the challenges presented to them by their relationships with their ex-partners. More disagreements or arguments arose from differences in styles of managing the ED behaviours. Diane had a good relationship with her ex-husband, but did notice the tension the ED created between them. Christina spoke about the tension her ex-husband added to her life during this time, but also how her relationship with her current partner was strained as a result of not spending as much time together as they were used to.
Often not spoken about in great depth, but important to bring to the surface, is the presence of other children. Not mentioned in her story, but in our audio recording, is Anna’s guilt concerning her oldest daughter: her need to be with her younger daughter meant that she did not get to drop off her older daughter at university. Similarly, Adrienne and Mila both felt that they missed events or the needs of their other children because they were so focused on the ED. As Adrienne said in regard to her relationship with her son during this time, “Wow, where did the time go? I feel badly. I feel like I’ve missed your high school, and I’ve missed who you are.” Mila also spoke about the pressure to try to keep things the same for their other two children, despite the chaos happening with her other daughter’s ED.

Friend and family relationships were also under pressure. Many of these women spoke about not having time or energy to go out for dinner with friends. Time and dedication invested in friendships were put on hold. Yona spoke about having friends that she can relax with, but also about not sharing too much what is happening in her life because “people always question everything.” Mila did not want to worry her family about the struggles she was having.

These women also had health needs of their own that created an additional pressure in their daily lives. Some of these health concerns were pre-existing, some related directly to ED caregiving. Mila spoke of her own doctor’s appointments taking a back seat to her child’s appointments, which meant that her own body was in constant pain. Rina spoke about being triggered herself through the ED experience, because she struggled with food as a youth. Many of these women also sought out their own mental health therapists, thanks to daily stressors. The
loss of employment, changes in their relationships, and the state of “high alert” that their circumstances required, all took a toll on their wellbeing.

An interesting aspect of all stories was their reflective questions. In asking them, they looked in on themselves. They wondered about their role in the onset of their daughters’ disorders, their responsibility, and what they felt they should not have missed. Diane talks about this as a normalcy, that it’s “what mom’s do, right? How can you not see it? You blame yourself … She’s your kid. How did you not know?” Mila spoke of a “rumination” that takes place in her mind, where she wonders what she is “bringing to the table” in response to this ED onset and the new behaviour in her child. She is reflecting on her actions and behaviours, wondering if she’s been interpreted as “neurotic, or super controlling, critical, you know, all the characteristics that they used to use to blame moms.” It is important to bring to light the ongoing self-reflection in which these women are engaged. I often feel that, as a clinician, we address this self-reflection and then immediately continue on by stating quickly that the cause of their mental labor was not their doing. Regardless, these questions continue to be top of mind. Despite longevity of experience, these women continue to have thoughts of self-blame.

**Concluding Remarks**

My concern in this chapter is the day-to-day lived experience of these women, and the pressures and stressors they face. These women’s lives have been consumed by the ED recovery process, with no guarantee that they will see total recovery in their children. They spend their time thinking, buying, and prepping food. They are monitoring meals and managing high emotions that come along with these meals. There is little time for much else in their life, as
evidenced by the enormous sense of loss that they have experienced: the loss of their jobs, the loss of the connection and time spent with their partners, the loss of participating in their other children’s lives, the grieving for time not spent with friends and extended family, and the loss of their own sense of self and the excitement of looking toward the future.

In order to know how to better support these women, we need to understand their day-to-day experiences, and the losses that come along with them. I highlight here the impossible demands faced daily by these women. Before rushing to fix, assist, or help, we need to understand how daily life is lived when an ED is present. We need to look carefully and deeply at their lived experience and felt expectations. Unhelpfully, I believe we have normalized their experience, leaving us oblivious to and unaware of the tremendous pressures felt by women who have a child with an ED.
Chapter Seven: 
Numerous Expectations Are Placed Upon Me as a Mother That Are Impossible to Meet

It is important to highlight that the women in this research inquiry were all in some capacity involved in the care or support of their child through the ED. In their mind, they had no option: they could not avoid being involved. In order to fully understand their lived experience, it is necessary to examine the expectations placed upon them – how mothers ‘ought’ to act in relation to their child with an ED. Conceptions of mothering, and their impact, are crucial here. The broad social environment is potent: how spouses, family, and friends tell them to act (intentionally and unintentionally), in addition to the expectations they place upon themselves.

As the ED unfolds in these women’s lives, their mothering expectations intensify while simultaneously being reinforced by their social networks. Even prior to the ED onset, women spoke about the mothering role, and especially the emotional aspect, as falling solely and exclusively on them. While some women mentioned that their partners acknowledged the challenges that they had taken on, such acknowledgement and awareness seemed rarely to lead to a change in the motherhood expectations and responsibility. Most notable among the messages received from family and social connections was that this caregiving was to be done in isolation.

Social Expectations: “I guess the perfect mother would be supportive, no matter what. I guess they wouldn’t be human then” (Anna).

Caregiving roles are typically expected almost exclusively of women. For many of the women in this inquiry, the labour of caregiving has been primarily their responsibility even before the ED surfaced. Mila spoke of being a stay-at-home mom until her children had grown, and then returned to this intensive role when her child was diagnosed with an ED. Cordelia,
Yona, and Gloria spoke of taking on more of the emotional labour than their partners. Similarly, Rina said she had always been more of the disciplinarian than her ex-partner. Essentially, well before the ED surfaced, mothers (as per expected gender patterning) were the expected prime caregiver and nurturer. It is also in line with Hays’ (1996) assumptions that mothers are the ideal, desired caretakers of children and that “emotionally absorbing, and labor-intensive child rearing is best” (p. 8). Intensive mothering practices are generally reserved for discussions of mothers with infants and young children, but this intensive mothering ideology appears to re-emerge during the ED. Many of the women spoke of the ED behaviours as taking them back to having a baby or toddler again. It appears necessary that women adopt intensive mothering ideologies again when their adolescent (and even adult) children are diagnosed with an ED. There is also the expectation that mothers want to engage in these practices in order to be seen as good, competent mothers. This ideology becomes very apparent in the stories that these women tell, even when their children are of an age when autonomy should be more evident.

Traditionally, women are also expected to put motherhood ahead of all other identities. The career woman role is sacrificed. A majority of the women in this inquiry were on some form of leave or accommodation, or were not actively seeking out employment, so they could focus on their children. Diane and Gloria spoke of feeling bored and unproductive at home and wanting to be working, because work gave them a sense of career and a feeling of competence, worth, and purpose. Yet they were both on leave to care for their children. Stay-at-home leave is not an option for all mothers; Christina, for example, explained that it was financially impossible as a single mom for her to do.
As a lone mother, Christina was unable to be all things to her child. She received the message that she was an inadequate mother because she was continuing in her career. Adrienne also continued on in her career, because it was the only place in her life that she felt adequate, despite the possible loss of her own self-care and well-being. Adrienne was waking up early to support her daughter, going to the grocery store multiple times a day, and staying up late. She admitted that there was no time to focus on herself and her own well-being. For her, the sacrifice was a loss of self: “I lost my mind. I lost who I was. A sense of being.” The expectation of self-sacrifice is evident for women when caring for a child with an ED, whether it be their careers or even their own time dedicated to themselves.

One of the most striking moments in all these interviews occurred when Anna was talking about her feelings of entrapment: “I remember that at the hospital and the first few months home thinking, like, ‘I have got to get out of here.’ And then thinking, ‘And I can’t.’” I could not help but question why she felt she had to stay. Surely, there are mothers that are not supporting their children through the ED. While in my mind I felt that these women had a choice to leave this role, “the notion of ‘choice’ rhetoric attributes women’s work status to their private and personal tastes and preferences and assumes that their decisions operate outside of any system of constraints” (Williams, 2000, p. 94). Essentially, women are not choosing to leave their jobs to stay in an at-times violent, intensive, caregiving role. They are pressured by social standards to continue on in their usual role. This is the expectation: to stay in this role “at great loss potentially to my health” (Mila).
Guilt is an emotion that is frequently associated with, and normalized in, motherhood (Sutherland, 2010). Guilt and shame result when there are discrepancies between a mother’s actual self and her ideal self (Liss et al., 2013). Women strive to meet the ideals of motherhood yet have vocalized that their actual self is “not enough and it tears you down” (Yona). Many of the women in this inquiry were attempting to meet the motherhood ideals within the ED context by attempting to be constantly available to their children. Leaving their careers in order to meet this demand, they carried out the roles of refeeding their child and supporting them through their intense emotional outbursts. Mothers were constantly reflecting on their own actual self and comparing it to the ideal mothering self. Mila illustrates: “I don’t have any benchmark to measure it on, the only place I can go is internally and being critical of myself. Am I balanced enough? … There’s this rumination that goes on as a parent, like what am I doing?” Cara also explained her own self-reflections when attempting to implement a new skill to help manage her child’s emotions: “Oh my God! I didn’t do anything right there. I didn’t get her to calm down. I didn’t do anything right.”

Feeling obligated to live up to this picture of motherhood brings up harmful emotions of guilt and shame, emotions that can lead to symptoms of depression (Kim et al., 2011). If a mother has a mental health concern, there is no possibility of her meeting the intensive mothering norms. Truly, intensive mothering expectations put women in a position of inevitable failure.

**Expectations from Family and Friends:** “Then it becomes 100% of my responsibility, her success or failure is 100% on me…. I’m quite sure [my husband] thinks that too.” (Cara)
While there are expectations put upon women through ideologies of mothering, especially intensive mothering, women also receive messages from interactions with meaningful others in their lives. Simply put, various relationships in these women’s lives have the effect of reinforcing the intensive mothering expectations. Messages about how to act, behave, and converse when you are a mother of a child with an ED are reinforced via interactions with intimate partners, friends, and extended family. The predominant message is that this caregiving role is for women, and that women’s caregiving is to be delivered in isolation.

The impact of interactions with meaningful others is huge. As a clinician, I would ask women to seek additional support from their partners, extended family, or friends, in light of the incredible demands placed on them by their role. When women replied that there was no one on whom they could lean for support, or they expressed their concern that people would judge, I mistakenly put the blame squarely on the women: “their own discomfort in asking for support is creating more challenges for them.” I would think to myself, “maybe they need to learn how better to communicate with their partners, extended family or friends in order to receive support they want.” However, this bias again puts the onus on women. It adds an expectation that they need to make changes in order to have their needs met.

Husbands communicate to their spouses that the ED caregiving role is typically reserved for women. The men do this by stating that they do not have the skills to take on this role. Mothers, they claim, have always been the better caregivers. Husbands were typically in supportive roles, or casual relief workers, such as making “sure that the bills are paid,” (Yona) or visiting the hospital for a few hours so women could have a shower and eat (Gloria). Husbands
were also described as being more of the “comic relief” (Gloria) or the “fun guy” (Cordelia), while mothers were the “jailer” (Anna), “tougher” (Diane) or the “bitchy, overstressed parent” (Gloria). This is not to place blame on husbands, but rather to highlight how ingrained these gendered norms are for both men and women. Discussions about division of labour does not take place. “He’s not home, he doesn’t come home and say, ‘I’m making dinner tonight. I’ll cut back a day (at work) so I can make the dinner and get the groceries.’ It really is still up to me. “Oh, well I’ll do what you want me to do,” I don’t want you to do what I want you to do, you just need to do it to be done” (Adrienne). The husband’s expectation here is to be told what to do, to be guided. Priorities clash: the women’s expectation of her husband is to provide support, while the husband’s expectation of her spouse is to be given guidance about how to deliver care.

Even Cara herself was unsure how to share this role with her husband. Meanwhile, her husband was suggesting that his intensive caregiving skills were not up to par. The result leaves women to take on the role: “It’s very hard to be “on” all the time for your kid, and then try to be on for your spouse as well” (Cara). Some women even received messages that their husbands were scared of their children, that they could not handle the emotions. Women again bear the heavy emotional burden. Inevitably, the messages from various sources leave the women to deliver care in isolation.

Indeed, the theme of isolation in these narratives is glaring, even when partners, extended family, and friends are available. In light of the women’s evident loneliness and isolation, I questioned whether this could possibly be a result of choices that they themselves had made, and not an expectation communicated to them through their interactions with meaningful others.
Women spoke of feeling judged by others, whether it was through others’ discomfort about communicating with them about EDs, or the disengagement they felt in conversations about EDs, or advice they received about how to help their children. These interactions led to shame: “we’re taught societally to not accept this behaviour, and you feel ashamed” (Mila). Such social teaching is reinforced through extended family and friends. “You do lose friends; people don’t get it. Family doesn’t get it. You can’t go back to that relationship anymore. The trust is broken. They’ve (parents) been blamed that they caused this” (Adrienne).

Women receive messages that they need to keep this matter private. Anna speaks of how people in her life “don’t know what to say and then they just feel awful too. … Everybody’s got their own stuff, so they don’t need more to worry about” (Anna). Anna did speak of having close neighbours who were helpful, but more so in the ways that husbands are “comic relief.” Rarely did women speak of extended family or friends stepping up to support the hands-on, practical, and emotional caregiving. Christina mentioned a moment when a family member did come to try and support her daughter, but because her child’s ED behaviours were intense, the family member did not offer to help again: “I don’t see anyone driving up on days to have lunch with her. They’ve offered and then once they did it and my [child] just had a meltdown. She left school… and nothing’s really happened since” (Christina).

Even service providers may have reinforced the impossible ‘intensive mothering’ ideology. Christina, for instance, said that “[the ED clinic] keep sending me information about taking a leave and collecting disability… but I can’t afford it.” Such communications from service providers suggest to women that they should sacrifice major pieces of their lives for their
child, despite the costs. Adrienne felt an expectation that she drop everything in her life and be present for all meetings, on top of reading the literature to get up to date on EDs. Diane commented on the stress placed upon her by “making sure that I met the dietary needs that they (ED team) wanted us to meet.”

Glaringly absent from discussions is the fact that many of these women have been supporting their children and participating in treatment for several months. Yet no change to the disproportionate work they have taken on has been considered. It leads me to wonder whether service providers are reinforcing the traditional gender divide while failing to alleviate some of the expectations placed solely on women’s shoulders. When discussion about sharing the burden does not take place – or only takes place when there is a breakdown in a woman’s mental health – it perpetuates the expectation that this is a role that women are to take on by themselves. I consider more fully the matter of the relationship of mothers to service providers in Chapter 9.

Significantly, at the end of the interviews women expressed their gratitude for having been able to share and freely express their struggles. Many spoke of the exchange as a unique experience and said that they felt emotionally and mentally relieved as a result. I had thought that friends, extended family, and partners had been listening to these women’s challenges, but the emphasis they placed on the uniqueness of the experience leads me to believe that they have not been able to have these non-judgemental and non-problem-solving discussions.

**Individual Expectations:** “I certainly got angry. I certainly raised my voice and said terrible things. You think ‘how can I say those things to my daughter?’” (Mila)
Even prior to the ED diagnosis, women had felt they should have noticed the EDs. Mila grew up with a sibling who had an ED. She felt that she should have known the signs as a result of this personal experience. Given her professional work, Gloria had felt that she could have been able to protect her child from an ED. Cordelia also said that she placed an “extra set of expectations on me, on if my children were misbehaved, how would that reflect on me as a team member at my place of employment” (Cordelia). As a result of Cordelia’s professional training, she put extra pressure on herself to prevent any sort of ED behaviours from surfacing. Women placed high expectations on themselves even retrospectively; they ought to have prevented the ED or at least to have noticed its signs earlier. As Diane has said, “That’s what moms do right? How can you not see it? You blame yourself. You blame yourself for everything because you think you should have seen it. She’s your kid. How did you not know?” The expectation is plain: women felt that because this is their child that they should have known or seen the ED emerging.

Once the ED was diagnosed and the women took on the main caregiver role, they mentioned the pressure to be strong or hide their emotions. Yona mentions the “Teflon suit” that she would put on when her child was verbally aggressive towards her, and how after those challenging interactions she could “go in the other room and … tear (cry) a little bit.” These women must not lose their calm. Cara spoke about having to prove that she can “handle” her child’s emotions and the demands of the ED treatment: “‘You can’t handle this.’ Yeah, and I literally stand there and go, ‘I have handled this so far. I’m not showing any signs of not being able to handle it.’” When Mila did get angry at her child, she questioned herself. Is she a good parent? Would a good mother not say things in a moment of frustration with her child? This
needing to handle and manage emotions in isolation leads to another major expectation: they must not fail. Responsibility for the child’s failure to do well falls squarely on the shoulders of these women.

“I’m not doing a good job with my kid if she’s not gaining. I’m a failure. What am I doing wrong? Guilt, shame, blame…” (Adrienne). Many women spoke about this expectation regarding weight gain and symptom cessation. Cara mentioned how this ED recovery is her responsibility, especially since she is carrying out the treatment on her own. In order to avoid failure, these women felt they had to do literally everything they could. Women spoke about the guilt and shame when they couldn’t meet the expectations of dedicating all their personal resources to their children. “Part of the guilt is [that] I’m not doing absolutely everything that I can all the time ’cause I just can’t. I feel a little guilty about that, and then I’m just sort of feeling guilty [that] there are a lot of negative feelings about her and about all of this” (Anna). This sentiment was also echoed by Christine, who felt “selfish” for wanting her life back, because despite her own wants, she felt she “should be doing everything” for her child.

The larger, more general societal expectations placed on women to be all things to all people is particularly true and internalized in the presence of an ED. Women spoke about this feeling of needing to dedicate all their resources to their child’s recovery. Yet it was still never enough. They placed blame on themselves for the ED and blame for not adhering to or doing treatment interventions perfectly. These women had an inescapable feeling of blame and shame that they could never be enough or do enough for their children. “You feel like a horrible failure
that you could not protect this person… you’re not enough and it tears you down, it really tears you down” (Yona).

**Concluding Remarks**

A major theme that runs through all the narratives with varying intensity is the notion of guilt, shame, and blame. These feelings appear to be a side effect of the impossible expectations that are reinforced from various sources. Unfortunately, this notion of guilt, shame, and blame are considered to be “normal” aspects of motherhood (Sutherland, 2010; Warner, 2005). But the consequences are harmful. Not only in general mothering literature but also in the ED context, intensive mothering ideology can lead women to emotional breakdown and depression (Pylypa, 2016). Quoting Pylypa (2016):

> And while it is tempting to emphasize that overstressed mothers have an impoverished capacity to parent well — and therefore such conditions are harmful to children, too — it is important to resist reinforcing a sacrificial motherhood perspective by focusing attention primarily on the impact on children, at the expense of concern for mothers’ own mental and physical health (p.441).

The burnout related to trying to do everything, and feeling that such extreme effort is failing, is a clear example of possible harmful repercussions. Women are attempting to maintain their sanity. They use their own limited time and money to see personal therapists in order to remain supportive for their children. Women should not have to be seeking out individual therapy so they can carry out the ED responsibilities placed upon them. Women are saying that they need more support, not therapy.
Another consequence of the expectations placed on mothers is the possibility of families falling apart. Anna, Gloria, Adrienne, and Cara all spoke at length about their relationship struggles and were not confident that their marriages would make it through the ED. When the intensive mothering ideology is an expectation of women, their children become the sole focus. The attention paid to all other social spheres goes by the wayside.

Women lost the sense of themselves through the experience of intensive mothering. Adrienne mentioned the lost joys in life. Anna mentioned thoughts of suicide. These women lost themselves in order to save their child. In accordance with the dominant motherhood ideology, that is what a good mother is supposed to do. Would a “good mother” have a child diagnosed with an eating disorder? The sense of failure experienced by many of the women in this inquiry seems to follow from their feeling of not being sufficiently proactive in interrupting the ED before it took hold. They had already failed to live up to the expectations of intensive mothering. While treatment models have moved away from blaming parents for ED onset, the ED outcome still weighs heavily on mothers. With recovery being heavily dependent on their interventions concerning ED behaviour, women feel the pressure to perform perfectly.

The ED places extraordinary expectations upon mothers. I cannot think of any other mental health concern where mothers have to take on the role of 24/7 nursing staff, for several months, even years, coupled with intense emotional caregiving for their child. It is imperative that we bring these issues to consciousness. Inquiry to date has not fully revealed the painful experience of these mothers and the reasons for it. Dominant theories of motherhood can be
readily seen as a way of understanding the effects of the expectations placed on women, rather than leaving them to individualize and personalize their actions and behaviours.
“You were a person long before you were a mom” (Yona).

I have thought about this phrase repeatedly. I believe that when women are seen in clinical environments, the motherhood identity is dominant. Scrutinizing my expectations of mothers, as well as revisiting interactions and conversations with my colleagues, supplies the evidence. A great deal of ED research has also focused on assessing mothers as primary caregivers who prepare meals and maintain households, and who also facilitate cultural and behavioural socialization of their children (Elfhag & Linné, 2005; Ogden & Steward, 2000; Pike & Rodin, 1991). In my experience, rarely are such women engaged as anything more than mothers of children with an ED.

Here it is important to emphasize other aspects of these women’s lives, aspects such as their careers, their social and intimate lives, and their personal health and wellbeing. I bring the fullness of the lives of these women to light in order to remind the reader that those we encounter in our clinical settings are not just mothers. Until the ED emerged, these women’s lives included other roles and identities beyond being a mother. Some still maintain these important parts of their lives during the ED.

Women frequently spoke about the various roles they added to being a mother: “I thought it would be more about feeding and still being a mom, but I’m not just a mom, I’ve got to be a mom, I’ve got to be therapist, I’ve got to be, you know, a health coach, I have to be, you know, a researcher, a dietitian” (Rina). I focus here not on these roles, but rather on the parts of these
women that are overshadowed by the motherhood roles, duties, and expectations that are exacerbated during an ED.

**Career Woman:** “That’s the only place I’m worthy” (Adrienne)

Elgar and Chester (2007) claim that, historically, research that has looked at mothers who work has focused on the effects of their working on the wellbeing of their children. It has not taken notice of the impact that work has had on women’s wellbeing. Essentially, when research began to focus on women’s dual roles of mother and worker, the study was focused on the negative expectation of the effect of work on mothers. Now, when research undertakes the association of work and wellbeing, it is typically “shaped by the way in which society has constructed maternal stereotypes. Mothering (good versus bad) and work status (employed versus at-home) have long been perceived as rigid binaries, each with stereotypical expectations” (Elgar & Chester, 2007, p.2).

While a majority of the women in this inquiry were temporarily off work, all of them took pride in their careers. Some had hopes of finding new meaningful work for themselves. These women worked in healthcare, education, and sales. Their careers were a place where they felt a sense of worth and competence. In my field notes I noted that when Yona and I were walking out of the interview room, she mentioned her work in machinery sales. I recall the pride in her voice as she spoke of being a woman who could tell you the machine needed for a specific task better than any other of her colleagues. She spoke about this unconventional image of being a woman who knows machinery, and how much she enjoyed learning about machinery for
specific jobs. I did not make this remark part of her formal narrative because it seemed part of a casual discussion. Now I understand how relevant this image was to her sense of self.

Adrienne and Gloria also spoke of the importance of employment in their lives. Adrienne continued to work as a healthcare professional who took great pride in helping numerous people every day and always being on top of her notes. Gloria was passionate about her career as an educator, but always felt that she never got to where she would have liked to have been in her career thanks to her commitment to child rearing. Mila spoke of just getting back into her art-based and education career after being at home with her kids for several years.

Many of these women took a leave from work when the ED emerged. Those that did not leave their work felt the pressure to make a decision to leave. Such was the case with Christina, who was a single mom who felt that she could not afford to leave her position. Adrienne felt that work was the one place in her life during the ED where she had some sense of accomplishment and self-efficacy. Anna mentioned how she was “really happy to be at work when [she was] there,” and Diane spoke of feeling “bored” and wanting to go back to work while she was off on a leave during her daughter’s ED.

Martikainen (1995) posits that women who are employed have moments of being temporarily removed from the repetitive, tedious, and unacknowledged work associated with homecare work. Work also provides an environment for social interaction and support that can alleviate the stressors at home.

While off from their jobs, women spoke about opportunities that they missed, how they “felt a loss all over again” (Gloria). Gloria was unable to contribute to a work project during the
time she was off caring for her child. Similarly, Cara mentioned how she just did not feel that she could take on any work-related opportunities. The tension between mothering and pursuing careers highlights for “professional” women the feeling that there is a clear divide between their private (home) and public (work) lives (Gatrell, 2013). For women who took a leave from their work, the identity change was challenging, especially when work was where they felt most capable.

Many of these women who were off of work had plans to return to work, or aspirations to revise their career paths. Rina and Yona were both in-between jobs and planned to return to job seeking. Cara, Mila, and Christina were reflecting on their future careers and whether they wanted to change into a different speciality. Cordelia spoke of having dreams of being on a “board of directors” and Mila spoke of wishing to give back after going through this challenging experience. Thus, even while on leave from their careers, these women still found work and careers to be an important aspect of their lives and aspirations.

**Social Selves:** “I get different things from different friendships.” (Yona)

Many of the women in this inquiry spoke about feeling that they were alone through this challenging time. Prior to the ED onset, women had greater connections with friends and co-workers. Many women said that they did not have the opportunity to engage much socially now. Those that continued to engage socially felt more restraints, and social interactions came with challenging emotions, such as fear of judgement from others. An example is Cordelia, who experienced “embarrassment” because of “having two kids that have anorexia and feeling very judged.” Yona was similar, of wanting to protect herself, her daughter, and also her friends:
“People always question everything. I play the cards with my daughter pretty close to my chest. I don’t open up too much about it because when I get negative feedback, I don’t want to rip my friends a new one.”

Mila, Cordelia, Cara, and Christina all spoke of wanting to go on vacation, be with friends and family, and how that aspect of their social lives changed with ED. Christina mentioned how every summer she went to Mexico with friends. She spoke of how her friends had booked that trip this year, but Christina was unsure if this was something she could attend now that she was the full-time and single caregiver for her child. Mila discussed how, every New Year’s, she and her family would go to a cottage with some friends and their kids, but the year Mila became involved in treatment for her child’s ED, she “didn’t get an invitation.” She spoke of “never [being] more devastated in my life, it was so painful and that was hard to share [that feeling] with [the friend]….We felt so isolated and sort of cheated.”

Yona spoke of having various friendship circles, some friends her age and others younger, some she would hang out with and just chat, and others that were involved in a bowling league or billiards group. She talked about how her social life had changed. She spoke of not wanting to risk losing friendships if a friend said something unintentionally harmful. Nonetheless, Yona spoke of seeking out social interactions to get her “cup full.”

Adrienne mentioned how she was “very careful who I spoke to” and came to the realization through this ED experience that some of the individuals in her life “really weren’t friends. None of those women reached out to me and said, ‘Hey, how are you doing? What can I
do to help?”’ Cordelia said that it was nearly impossible to be with others socially: “If I was invited for lunch or dinner, I couldn’t go,” and she spoke of being forced to be isolated.

While a majority of women commented on the increased isolation, others mentioned that they still interacted with friends, specifically for support for themselves through this challenging time. For example, Rina spoke of talking to friends about her own challenges concerning food and being “triggered” with the focus on food and weight through the ED process with her child. Diane mentioned how her friends “were always contacting [me] to see how things were going.” Gloria also spoke of having a friend who reached out to her repeatedly. The women who maintained social connections described having conversations about their own exhaustion and struggles during the ED. It was no surprise when these women also spoke about their own guilt about sharing their struggles with friends when “Everybody is maxed” (Gloria) and when “Everybody’s got their own stuff, so they don’t need more to worry about” (Anna).

**Partner Relations:** “[W]e’ve worked really hard our whole lives to make sure that we still know who each other is, and that we are still in tune with each other.” (Cordelia)

Van Laningham et al. (2001) speak of marital happiness as having a U-shaped pattern, whereby happiness is at a peak early on in marriage, with a decline when children and parental responsibilities are present. Feelings of happiness take an upturn during the post-parental years. The majority of women in this inquiry had children at ages where their autonomy typically is increasing. Often this is a period when relationships with partners begin to increase in satisfaction. Mila spoke of this as a time when their “heads [were] above water,” and she and her husband were starting to “travel a little bit together.”
Adrienne mentioned how the ED brings up the “shit in your marriage, and then makes it shittier.” Many of these women and their partners struggled at times. Cordelia mentioned how she and her partner would talk before bed, or have some intimacy, but now she says they “zonk out.” She also mentioned how she and her husband had to work hard to make sure that they still know each other and are “in tune” with each other. But they were no longer spending as much time with each other. Yona spoke of building things with her husband, saying both were interested in home construction, and being “couch potatoes” together. Christina mentioned how she and her partner would have “adult weekends” when they would go camping together as a couple. The literature indicates that having a child with an ED can impact the quality of a partnership (Latzer et al., 2009), although it should be mentioned that marital conflict was traditionally viewed as a cause of ED onset.

Intimate relationships paid a toll as a result of the time and energy that the women had to put into their child’s care. Cara said that “all my emotional energy goes into [my daughter]. I cannot deal with [my husband].” Cordelia and her husband used to take “mini trips away” to reconnect with each other, but through this ED process, Cordelia says that they “just don’t have that opportunity anymore.” Anna talked about the stress that the ED has had on her relationship, to the point where she and her husband had discussions about splitting up. Through couples counselling, they realized that what they fought about as a couple was how they dealt with their daughter’s ED.

Cara also mentioned the emotional and mental toll of the ED on her and her husband’s relationship. She mentioned that because she is dealing with her daughter’s ED, and her husband
is “dealing with his own anxieties,” “neither one of us has time for each other.” Adrienne spoke of the “disgust” she feels when she looks at her husband now. Adrienne reflected on a comment on an online forum for parents who have children with an ED:

Someone put up a thread, “How do you save your marriage?” And it got me so angry. You know, “make sure the bedroom is ED free.” Fuck that, I have three kids. The only place is the bedroom to talk about [the eating disorder].

Adrienne’s husband’s lack of support led her to be resentful that they were not in a partnership: “Don’t touch me. Don’t look at me. You’re not helping me.”

A majority of women had hopes for the future for their intimate relationships. Many had hopes that, as a couple, there would be a reconnection and repair of their intimate relationships. Cara acknowledged that there would be some “repair work” needed for her and her husband to reconnect after what has happened to them as a couple during their ED experience. Others, such as Adrienne, remained skeptical about how they could reconnect with their partners after the ED.

Health and Wellness: “I just need to decompress, I need to just sit, stare at my Facebook account, watch some mindless television show for half an hour just go decompress my brain because I’ve had to be on all day.” (Christina)

Beyond being a career woman, a friend, and a wife or partner, the women in this inquiry also had their self-care needs. Diane, Cordelia, and Christina mentioned the importance of exercise in their life. For Diane, taking care of herself was going to the gym: “that’s my pill.” Cordelia mentioned going for walks around the indoor track to “zone out,” and Christina spoke of soccer, kickboxing, and the gym to keep her active. Yona had clubs that were both social but
also for exercise, such as billiards and bowling. Yona also spoke of exercise in connection with her needing to keep her sugars at a healthy level. For Mila, exercise and movement were crucial for relief of the pain from her autoimmune disease. Anna said fostering puppies in her home was a stress reliever and gave her something else to focus on. Adrienne mentioned how she took pride and joy in fashion and jewelry.

When the ED emerged, many of these personal activities that women had in their daily life went by the wayside. Mila had to cancel all of her own appointments: “My whole health, my wellbeing, I stopped exercising because it’s difficult to exercise when your daughter has an eating disorder.…[I] stopped doing a lot of things that used to bring me a lot of joy.” The loss of the other “selves” through work, social activities, and relationships likely contributed to diminished wellbeing. Many of the women spoke of their own mental health deteriorating: they felt lonely, they grieved for the loss of selves, and they felt inadequate. Many women sought out individual therapy to maintain some semblance of mental wellbeing.

These women had aspirations for their own wellness. Cara wondered about taking up a hobby in the future, something art-based, as well was going to the gym more. Anna hoped to continue to foster rescue dogs and hoped to volunteer more. By our last session, Mila had told me that she had made a plan to move more, in some capacity, for her own physical health.

**Concluding Remarks**

The ‘narrative’ form has been described as “the primary scheme by which human existence is rendered meaningful” (Polkinghorne, 1988, p. 1). Thus, in order to fully bring meaning to the narratives for these women, a focus beyond being a mother is necessary. In my
literature review, I came upon a mere handful of articles that discussed caregiver burnout and
distress in the ED context (Haigh & Treasure, 2003; Martin et al., 2013; Treasure et al., 2001).
Rarely, if ever, was there a mention of the lives these women had prior to the ED onset, and how
this change affected the other areas of their lives. Often there was discussion of feelings of
isolation, lower quality of life, and measures of anxiety and depression in caregivers. The focus
was also on the experience and the burden of the caregiving for the child with ED. But for these
women, there is another layer beyond mothering: the other important parts of their lived
experience.

It is important that researchers and service providers look holistically at women, beyond
the role of mother. When we focus on the mother and her roles, we often lose sight of the person.
We must include in our discussion the other roles that are important to women, and their grieving
over the diminishing of these roles. We must support women in order that they regain these
important aspects of their lives. When we lose sight of the whole person, we become less helpful
than we can be.
Chapter Nine:  
I Was Grateful These Services and Service Providers Existed, but I Needed More Support

Women who are engaged with their child in eating disorder (ED) treatment are interacting with various services and professionals on an ongoing basis. Due to the complexity of EDs (medical instability, high mortality, chronicity, comorbidities), women often have to navigate diverse systems throughout the course of the ED (residential, impatient, outpatient, community setting). Women also have to interact with many service providers within these various systems as ED treatment often involves a multidisciplinary team (Joy et al., 2003). The purpose of this chapter is to bring forward the interactions these women described with ED services and service providers.

The women in this inquiry were engaged at some point in treatment with the Family Based Therapy (FBT) model of intervention, or at least components of that model (with the exception of Yona). FBT has been described as the most researched program with the most promising outcomes to date for child and adolescent eating disorders (Couturier et al., 2020).

I Was Grateful These Services and Service Providers Existed: “It’s a good thing that there’s the support systems.” (Diane)

Despite challenges, these women were grateful that they were able to access and participate in services for their child’s ED. Mila mentioned how her sister had an ED in the 70s and that families were “never part of the therapy, we were kept very outside of the eating disorder.” Diane mentioned her positive experience with her child’s primary care provider. This provider assessed Diane’s child for ED symptoms and immediately made a referral to a local ED program. Rina’s daughter was being followed up regularly in a pain clinic. The pain clinic
quickly noticed the weight loss and recommended a referral to an ED program. Although Gloria mentioned challenges with the hospital when her daughter was in crisis, she did say how the hospital connected her with a youth crisis worker in the community. Gloria felt it was “the most valuable thing.” It was this crisis worker that linked Gloria to an ED program in the community.

Diane felt her local ED clinic went “beyond… they met [my] expectations” and felt the team were skilled professionals. Intensive hospital programs for some women were a “saving grace” (Diane) and provided some respite from the ongoing care, and some reassurance of their child’s safety. Anna felt “relief” knowing their children were receiving care by professionals that had specialized knowledge of ED. While her daughter was in a residential program, Mila had a break from her daughter’s suicidal text messages and was able to take time to address her own health concerns. Cordelia mentioned that her older child had been to a residential treatment centre, so she knew that more intensive option was available. She saw this option as helpful and necessary. For Diane, her experiences at the ED clinic “were beyond… they met [my] expectations. I think it was really good.”

Navigating the Systems Was Not Simple or Straightforward: “They kept saying, ‘we’ll keep her as long as we can, but she could be discharged any day.’ Then we literally had two hours to get out when they told us it was time to go, with no warning the day before or anything.” (Anna)

The women in this inquiry found themselves entering the ED systems through different pathways. Some women had an intuition regarding their child’s behaviours and sought out their primary health care provider (see Diane, Anna, and Adrienne). Others arrived through contact
with other non-ED health care practitioners who were focused on general health or mental health concerns (see Rina and Cara). For some women, their entry into the ED world was through an emergency service (see Gloria and Mila). For example:

I really feel like [the pediatrician] missed the boat, [and] everybody’s careful not to come right out and say it but you could tell from the other professionals. I guess you can’t be [up on the current knowledge] for everything, but this is one that pediatricians and family doctors need to catch a lot sooner […] we might have had a better chance of getting it earlier (Anna).

This is not a new observation. Beale, McMaster, and Hillege (2004) noted that many parents’ journeys started with “a denial by the sufferer as well as some health professionals/counsellors to whom the parents (sic) first turned in the first instance. The first point of contact was often fruitless and left the parents to search for their own answers” (p. 127). Lafrance Robinson et al. (2013) also reported that professionals themselves noted a dearth of formal training about ED identification.

Gloria went “from a therapist’s office to an admission at [local hospital]” due to her child expressing suicidal ideation. Gloria said that her child spent eight days in a hospital bed, not receiving care for the ED, until Gloria expressed the need for her daughter to be in a hospital with an ED unit. Her daughter had lost 20 lbs while at the hospital. “So eventually they sent us to [another city’s child and adolescent unit and] they sent us home in less than 24 hours. ‘This kid’s fine. […] ‘She doesn’t have an eating disorder. She doesn’t meet the diagnostic criteria.’” Gloria mentions how a community
worker who was with the family informed them of a local, outpatient ED service to which they were referred.

Some women were fortunate to have contact with professionals with knowledge of EDs who could refer them smoothly into an ED program. For others, it was a struggle. These women entered into the ED world already frustrated and exhausted.

Once in contact with specialized ED services, additional challenges were faced. Christina mentioned how she had to take off one day from work weekly because the organization only had ED clinics on Tuesdays. For Diane, and several other women, they had to navigate the change from an ED outpatient clinic to an acute care hospital to another hospital that had a specialized ED unit. Several women in this inquiry had children that required inpatient admissions. These women often had to drive over an hour daily to be at the hospital with their child.

Mila’s daughter had been in inpatient ED hospitals, but had a need for more intensive care that residential treatment provided. There were challenges with the referral being misplaced, and once her daughter was admitted, challenges remained:

Why do they not tell me what’s going on? My anxiety didn’t really get any better because she was calling us from [residential program] freaking out, crying, every day. We had minimal information still at that point, this is like three weeks into the program. Those administrative issues have made the admission into residential care very difficult, has added to the anxiety and the stress. You kind of think ‘it will be great, I’ll be able to get a bit of reprieve and my daughter’s going to be
getting 24-hour care immediately when she needs it’, but it’s not that way, and that was difficult.

Yona spoke of the challenges of having an adult-age child and not being allowed to know details of her child’s treatment, despite having booked the appointments for her child, driving her child to appointments, and researching services to support her child. She said that the process of getting her child support took almost a year: “I never know what’s going on. […] Some people tell me one thing and some people tell me something else. I’m not allowed to participate […] only the once I was invited [to the] eating disorders (parent) group.”

Attention to how women find, enter, and traverse these systems with their children and families is important. As individuals who are diagnosed with an ED typically resist treatment (Fassino & Abbate-Daga, 2013; Halmi, 2013), it is mothers who typically are the catalyst for the individual receiving support. The journey into the ED world is not simply seeing a physician and getting a referral. It is far more complex and difficult. For these women, the journey was rarely as simple as getting a referral, entering into a program, and continuing with one treatment modality (e.g., FBT) or a single setting. They had to be flexible, shifting through the different expectations of various systems.

**Components of FBT Were Helpful:** “To some extent it’s working” (Anna).

FBT is a manualized treatment for anorexia nervosa and bulimia nervosa. There are some specific components intended to be present in FBT: all family members attend, parents refeed
their child, the child’s weight is monitored, there is a family meal, and discussions are directed (or redirected) towards symptom interruption and refeeding (Kosmerly et al., 2015). FBT is designed to be behaviour and educational focused, especially during the beginning phases. As such, the interventions associated with FBT are defined in relatively straightforward terms, although challenging to implement. FBT is intended to focus on creating a “zero tolerance environment for the eating disorder” and fostering parental empowerment.

Cordelia had said that, despite the challenges encountered, “[Family-based therapy] is working for us.” She felt that FBT provided lots of “solid strategies […] a lot of suggestions, a lot of alternatives and a lot of clear direction” to help her through the refeeding stage with her child. Anna said that, despite how challenging this model was to implement, “I think it’s working because she’s eating now. At least to some extent it’s working.” Anna mentioned how the FBT model led to alleviating her feelings of guilt: “I think that was good. Hard but good, because you know what you need to do, so you don’t have to feel guilty.” This idea of FBT being “hard but good” is echoed in Krautter and Lock’s (2004) study, whereby one individual said: “It was very difficult, but successful.” (p.72)

Diane felt that by doing FBT she became closer to her child. She spoke of paying more attention to her child and having more “one-on-one time” with her. She said that the communication between her and her ex-husband improved and brought them closer.

There are few research studies that focus on the satisfaction of women involved in FBT. Krautter and Lock (2004) reported from their research with 35 mothers and 31 fathers that these parents felt highly positive about manualized FBT. Because this study “intended to evaluate
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patient satisfaction of the entire treatment process, only families who completed treatment were enlisted into the study” (p.69). Their results indicated that 33 of these mothers would recommend FBT to others (Krautter & Lock, 2004, p.77). It is important to mention that Krautter and Lock’s (2004) study requested that both parents and all siblings attend sessions, which differs from many of the women in this inquiry who were attending sessions without their partners and without other siblings.

I Needed Better Communication About FBT: “I need more information. I need to know more about what I’m supposed to do here.” (Cara)

Looking at how these women entered into the ED world, it made sense that some women identified a need for a road map. Cara expressed that she wanted an overview: “You want somebody to say, ‘Okay, this is your roadmap. […] You could be feeding them for a year, two years, whatever, but that’s what you’re going to do first and then you’re going to do this.’” This is echoed in Beale, McMaster, & Hillege’s (2004) research, where parents expressed the need for a guide to navigate this “uncharted territory with no clear destination” (p.131). Rina concurred saying that she was “flying blind” through FBT treatment. Adrienne said that “nobody explicitly said, ‘Let’s pretend you know nothing and go through everything, to make sure we have no gaps in knowledge.’ That is where I feel there’s a huge disconnect.”

Some women described receiving a rushed explanation of FBT. Adrienne said that she was given a book to read. Gloria described a “one-hour primer on family-based therapy. Go do it.” For many women, this lack of clear guidance led them to seek out information on their own: “I had to go to the Internet. My team couldn’t help me” (Adrienne). McMaster et al. (2004)
found that while parents were relieved once they found help, they also needed additional informational resources.

Adrienne said that having a list of grocery items that are higher in calories would have been helpful. Several women stressed that they were not warned about the conflict at home that FBT would evoke. Adrienne described the immense shame that she felt when violence occurred in her home. She believed that she could not speak about it to clinicians who had not communicated that this was a potential outcome of interrupting the ED symptoms. McArdle (2019) postulated that the avoidance of such discussions may be due to service providers’ pessimism towards treatment outcomes for ED.

Rina also expected far more information about the treatment modality. She explained that she thought that an intensive education day could have been helpful:

This is what it’s going to be like as a parent [in FBT]. Here’s how it works out over the time scale. Here’s how it looks like progression wise. Here’s some of the things to expect from your child. […] Here are some behaviors you may see happening. Here’s what you need to be aware of.’ I didn’t feel like there was a lot of that. I felt like it was very much like you went in, they tell you about the program, here’s a book you need to read. It’s almost like they service this third-party tab, honestly. I feel like it’s more like they’re keeping tabs on [daughter].

Overall, women felt that engaging with FBT was a challenge in part because of a lack of communication and lack of structure in the program. Rina said that “there’s so much left up to parental discretion that that’s the exhausting part. There isn’t enough specificity.”
Separating the challenges with FBT and the challenges with service providers was a difficulty faced when writing this chapter. Service providers do have to interpret and translate what they read in the FBT manual into practice, which as noted can create dilemmas. This interpretive process may have led to communication challenges with women in this inquiry. This will be further discussed in the final chapter.

Service providers face their own set of challenges when implementing FBT. Aradas et al. (2019) discussed the challenges and dilemmas FBT service providers faced:

- clinicians were troubled by the core FBT-AN premise that it is reasonable to ask parents to take on primary responsibility for refeeding their child and the emotional and material effects of this. Implicit in these clinicians’ arguments is the extent by which the FBT-AN model risks under-acknowledging and underestimating emotional and material cost on parents who are asked to take responsibility for re-feeding their child in the early phases. (p. 7)

Rienecke’s (2017) article states that “additional parental coaching may be particularly welcome, given the stress that can accompany caring for an individual with an eating disorder […] Although FBT can be an intense and challenging process for parents, parents’ experience of FBT has not been well documented. Anecdotal accounts suggest that it can be quite difficult” (p. 76). Clinicians may be left to decide whether to add individual supports for women that are not outlined in the FBT model.

Some women said that the services providers using FBT did not give adequate space for them to communicate their own struggles and emotions. Diane said that the clinicians using the
model did not really check in on how she was doing throughout this process: “It wasn’t how personally are you doing.” Similarly, Cordelia felt that FBT service providers offered a lot of “solid strategies,” but added: “I wouldn’t say that a real strong point of family-based treatment is the looking at mom and how that person’s doing.” Many women spoke about the negative impacts that this lack of attention had on them. Adrienne and Mila described having “PTSD” from their experiences.

Anna mentioned waiting several days or weeks before she could speak to a service provider. She said that there was a sense of urgency and crisis communicated by service providers, but this was contradicted by the lack of immediate support. FBT service providers are supposed to intentionally elevate parental anxiety by having a “somber discussion of the medical complications of anorexia, which aims to render the anxiety parents feel about not confronting their child’s anorexia greater than any anxiety around confronting their child’s symptoms” (Murray et al., 2015, p. 307).

FBT service providers are supposed to explain to parents that weight restoration is “orchestrated by parents” and that parents are “given responsibility for deciding what their child eats, how much is eaten, when it is eaten, and monitoring all food intake, and generally curtailing physical activity” (Rienecke, 2017, p. 70). The FBT service provider’s work is to “empower parents by putting them in charge of the process and communicating to them that the therapist has confidence in their ability to beat the eating disorder” (Rienecke, 2017, p. 71). Women in this study clearly expressed feeling personally responsible for the outcomes of treatment. When there
was a discussion of changing the treatment or recommending a higher level of care for the child, there were feelings of failure that they “had not managed [at the local ED program]” (Mila).

**The ED Therapist Legitimized What I Was Doing and Gave Me Space to Process Emotions:** “Thank god for [ED therapist]” (Cara).

Many of the women said that they trusted the service providers as the experts and followed through on recommendations. But beyond being experts, many of these women spoke of the service providers being helpful. Many women (Anna, Diane, Gloria, and Cordelia) had their own (separate from the ED clinic) therapists. Some ED therapists did have individual sessions for just the women, without their child present.

Mila’s ED therapist spoke with her individually about the intense feelings she experienced. Mila spoke of “shedding tears” with her ED therapist at times when she was overwhelmed: “I said to [the ED therapist], ‘I have never felt like this, ever in my life where I don’t feel particularly safe, my thoughts are abnormal.’ [I’ve only shared this with] [ED therapist], thank god for [ED therapist]” (Mila).

Cara spoke of relying extensively on her therapist. She said that her therapist worked with her individually to “get to the bottom” of what she was experiencing and feeling. Her therapist used various therapy approaches to support her through the ED. Cara mentioned that her ED therapist checked in to ensure she was safe and gave space for Cara to express moments when she did not feel safe at home when her child became violent.

Some women also spoke about comments that validated how they were doing caring for their child and tried to remove any blame. Gloria said that the professionals stated that she had
done a “good job” caring for her daughter, especially with how “unwell” her daughter was. Anna said that a service provider had explicitly told her that the ED was not her fault. She was reassured that what she was doing was not “like child abuse,” but rather she was “preventing her (child) from hurting herself.” Mila mentioned that her ED therapist validated that it was not unusual that Mila felt uneasy about the treatment facility that her child was residing in.

Adrienne spoke about the support from her ED therapist: “No one told me (what to do) if she (child) calls the police […]. I had to ask for that from [ED therapist] […]. She was very good about saying, Adrienne, if this happens, you give them my card, and my phone numbers.” Adrienne felt that her ED therapist was “very, very, open” and hears her.

Overall, many found that the ED service providers created a safe space where they could express the turmoil they were going through. Several women also felt that their service providers were listening actively to what they had to say and that they made reinforcing, validating statements for these women when going through the ED treatment process.

I Sometimes Felt Judged or Misunderstood by Service Providers: “Sometimes I feel like they look at me like, ‘Why aren’t you doing more?’ I feel like I’m doing the best I can do.” (Christina)

McMaster et al. (2004) reported that parents experienced “many negative interactions with health professions during their child’s many hospitalizations” (p.70). They were aware of service providers holding “stereotypical images of patients with eating disorders and their parents” (p.71).
The ED world has changed its official focus from parent blame to parent empowerment (Dimitropoulos et al., 2017; Le Grange & Lock, 2007; Lock & Le Grange, 2013). However, despite such efforts, many mothers in this study were still feeling judged. When Mila’s child went to a residential program and she was left without information about the program, she sent emails and phone calls that for a long period of time went unanswered. This left Mila distrusting the program where her child was residing. She felt that the residential ED staff may have seen her as a “shit disturber […] neurotic, or super controlling, critical, you know, all the characteristics they used to use to blame moms.”

Anna also felt that service providers viewed her as “a crazy mother,” “too soft,” and that her daughter’s “been running the show for a while.” Anna worried that service providers thought that she was not a good mother: “Are they thinking that I’m making it worse or are they thinking I’m not doing a good job?” Anna mentioned how a comment from a service provider that her daughter was unlikely to get better at home led to her feeling confused about why her daughter was being discharged to her care. It also negatively impacted her confidence that she could support her daughter. She noted that she felt minimized and dismissed:

The professionals tend to come back with, ‘Yep, that’s fairly typical of eating disorders. We see this all the time’ It feels crappy to have to be treated like, ‘Oh, yeah. We see this all the time with parents.’ That just feels not very good.

Christina spoke of consistent discussions with service providers around changes that she needed to make to support her daughter. She explained that she felt “judged” and wondered if the service providers were looking at her thinking “why aren’t you doing more?” She stated that the
recommendations made by service providers to set an alarm earlier, to have breakfast with her daughter, to pack a lunch even if it will be thrown out showed a lack of understanding of the realities of a single mom. This lack of feeling heard and understood by service providers was echoed by Anna:

> It’s a bit condescending that the experts know, and that parents don’t. I don’t believe that’s how most of those people really feel, but I think just listening to what parents have to say is good. And they always sort of do, but maybe not really giving it the weight that it needs to be given.

Adrienne felt that she had “offended” service providers when she gave feedback that they needed to “do a better job” of educating parents and providing helpful resources. She spoke of the lack of openness that she felt from service providers: “You’re asking me to be open with my feelings when I come in for my appointments. Why can’t you be?”

Some women felt uncomfortable discussing with service providers how their interactions impacted them. Christina says her reason for not saying anything was “because they’re the professionals.” Mila echoed this caution. Because Mila’s daughter was in a “locked facility where she is at the mercy of other people” she did not want to have her behaviours impact her child’s experience at the program.

**Concluding Remarks**

These women had varied pathways that they followed to arrive at specialized ED services. Some had a relatively straight-forward journey to receive appropriate ED services, while others confronted complicated and difficult entries to ED services. Many faced many
difficulties both with the ED treatment modalities and their relationships with service providers. These women almost always went through lengthy and substantial struggles to get their child into appropriate care, and then were tasked with the very demanding role of being “the main therapist” (Adrienne). Despite these challenges, many women said FBT was working, their child was gaining weight, and they noticed some improvements in their child’s mood.

As the main therapist for their child, they had a sense of “flying blind” (Rina). Treatment, for some women, felt more like a “third-party tab” (Rina) monitoring whether women were implementing the prescribed treatment in their home, and problem solving with the service providers when challenges arose. When problems inevitably arose, some women felt unheard by their service providers. This was not the case for all women. Some women spoke about the safety that they felt with their ED therapist. They talked about speaking individually with the ED clinician, and processing the heavy emotions that they were experiencing. Some women felt their therapists were good listeners and provided positive, encouraging feedback.
Chapter Ten: What Can We Learn?

“I think I’ve saved her” (Mila). Heroic. Strong. Altruistic. Fighter. Superwoman. These words could be used when describing the women in this paper. These women have taken on an extreme caregiving role; they may have saved their children. But at what cost to them? They are often the advocates for their children, but who are the advocates for these women?

As a clinician, I used to think I was their advocate. I’d be their “coach,” encouraging them to *stay the course*, to *keep going* despite the distress, like a personal fitness coach, but for emotional turmoil, strengthening their resistance to emotional distress. I would normalize the distress, saying that this was typical through the ED process. And when women vocalized their doubts about how long they could do this work, I’d praise their vulnerability and encourage self-care: yoga, mindfulness, taking a walk, having a partner (should they have one) take on more responsibility. I’d praise these women for “hanging in there” and for absorbing verbal and even physical abuse.

I viewed the women’s survival strategies (Yona’s “Teflon suit,” Cara’s “numb[ness]”) as strength. I now believe I was passively witnessing psychological trauma. I normalized the experience. I believed that continuing under duress was what women should do. By praising their strength and their tenacity, labelling it “super mom” or “heroic,” I failed to ask, “What do you need?” And I failed to ask, “What is the cost of this enduring?” In rare moments, when I saw a woman breaking down, my brain automatically went to, “She needs self-care, because if mom isn’t well her child cannot be well,” or “I need to teach her more skills, so she better manages the ED behaviours.”
The women in this study are strong but they also are struggling and often suffering. These women were not full of energy when speaking of the trials they endured, typically on their own:

“But I’m at a point where I feel I’ve done everything I can do in life. I’m done with life. I’m not suicidal. No. But, it’s okay to die now. But not in a good way. Not because I’m happy. But because I’ve had enough. There’re very few things I find pleasure in” (Adrienne).

These were untold stories. I believed that we needed to hear from women who were on the frontlines in order to support them better. Through reflecting on my clinical practice and the stories of the women in this research, I realized I never knew or asked about the personal consequences of their experiences. I didn’t know about their pain, their shame, or the pressures that they felt. I never considered what they had given up. In the literature, we hear snippets of their experiences, but it is all in relation to the ED and the child. The woman’s personhood is lost, eclipsed by her motherhood identity and its relation to eating disorders.

One of the first findings of this inquiry came from my recruitment. Recruiting participants was rapid; women wanted to share their story. Maybe they wanted to share as a cathartic experience, or maybe they hoped it would lead to change and better support for others in similar circumstances, or maybe they wanted to have their struggles acknowledged. Whatever the reason, they needed to tell their stories, with themselves as the main characters, in their own words.
Gender is often removed from the literature, perhaps to escape from the historical mother-blame in the ED literature, or to encompass the diversity of caregivers (intimate partners, aunts, uncles, fathers, grandparents, siblings). However, caregivers of children with an ED are predominantly women who are mothers. Women, specifically in Western contexts, encounter and absorb motherhood ideologies that inform their expectations and behaviours about what they should do for their children. When we use words such as “parents” or “caregivers,” we fail to adequately acknowledge that the caring role and responsibilities remain women’s work:

Awareness of gender and gender inequality has long since penetrated not only family therapy but also our entire culture. Translating this awareness into clinical practice, however, is complicated. [...] It is not possible, however, to be a fair and effective therapist without being sensitive to how gender issues pervade the life of the family. A therapist who ignored gender may inadvertently show less interest in a woman’s career, assume that a child’s problems are primarily the mother’s responsibility, [...] and expect – or at least tolerate – a father’s non-participation in the family’s treatment (Chodorow 1978, cited by Nichols & Davis, 2020, p.52).

That said, I conducted this research principally because women matter beyond being a means to an end for their child. They matter not because their child depends on their wellness; rather, they matter because as individuals they have a need and a right to be well. This may be an obvious, unobjectionable statement, yet I believe that it is not being translated into practice. I believe services and service providers have subscribed to,
and perpetuated, the notion that women should be the prime caregivers, that they should
dedicate all their resources to helping their child, regardless of the cost to themselves.

It can be tempting to review theories as to why women are generally the main
caregivers. I often justified my own expectations of mothers. Theories spanning
evolutionary, biological, feminist, psychoanalytic, and anthropological fields attempt to
understand this pattern (see: Mayseless, 2016, Chapter 15). However, theories that
attempt to explain why women take on these roles miss this reality. Regardless of
explanation, women are in these roles, and they are struggling. Women are the prime
caregivers: they are tasked to take on an extraordinarily burdensome challenge, and they
are expected to sacrifice many important aspects of themselves. This research seeks not
to explain why they are in this situation but asks what we can do to lighten this difficult
role.

A Persistent Battle: Pressured to Navigate a Chaotic and Arduous Context

Women facing child ED talked about themselves as a “jailer” (Anna) and “benevolent
dictator” (Adrienne). Women described the ED experience as “conflictful” (Gloria), a “living
nightmare” (Cottee-Lane et al., 2004), and a “battlefield” (H. J. White et al., 2020). I have
hesitated to call this experience a ‘battlefield’ or other conflict metaphor.

However, I believe this to be a useful analogy. It conveys the intense struggle that women
experience for a prolonged period of time, with multiple battles, and women “just want to
survive” (Gloria) this “long, arduous journey” (McMaster et al., 2004, p. 70). The women in this
study were battling against the ED to rescue their child and protect her from death.
The code of conduct for a mother are responsibility, sacrifice, dedication, and love. Mothers are indoctrinated into “intensive attachment parenting principles,” even at the expense to their own well-being (Pylypa, 2016, p. 441). Women do not have to take on these prescriptions; however, they will likely be labeled a ‘bad’ mom if they do not. “I remember […] thinking, like, ‘I have got to get out of here.’ And then thinking, ‘And I can’t.’” (Anna). The clinician in me thinks, of course she can leave and choose not to participate. But the commitment to ideals of motherhood prevents women from escaping. We have not given adequate attention to the day-to-day pressures these women endure. We are not giving adequate attention to the realities that women are taking on this role, the pressures they confront, and the losses they typically suffer. As one clinician in Aradas et al. (2019) expressed: “Probably we underestimate how difficult it is for parents (sic) to treat their young person” (p.4).

**Disproportionately, It Is Women Who Take on This Demanding Role**

I focused this inquiry on women as a result of reflection on my own practice. It was women who attended treatment with their children. It was women planning meals and scheduling appointments. It was women recalling the week in therapy sessions. My clinical experience is echoed in literature, albeit sparsely. In the research literature, parent samples consist primarily of mothers (See: Accurso et al., 2020; Fox et al., 2017; Hughes et al., 2020; McArdle, 2019; Weaver, 2012). Hughes et al. (2017) report that siblings and fathers typically drop off from treatment, while mothers and the child patients remain in attendance. There are sometimes cursory indications of this reality in literature, such as in Rienecke et al. (2016):
it is typically mothers that take on this responsibility [for caregiving] and take time off work, while fathers continued to work full time. It is possible that the caregiving burden involved in family-based interventions more frequently falls disproportionately on mothers (p.127).

Sepúlveda et al. (2012) also notes that the caregiving burden falls primarily on mothers and recommends that fathers participate more in treatment. It is tempting to simply recommend that fathers take on more of the burden and leave the onus almost entirely upon families. But in doing so we fail to acknowledge the motherhood ideology and the social context that places women at the center. We also fail to ask ourselves whether it is either fair, necessary, or sufficient for mothers or even families to carry such burdens with minimal help from outside people and resources. This perspective also absolves us from thinking about what we could do to help alleviate such pressures over time.

Women do feel responsible for how their children turn out, and when their children experience challenges, women feel blamed and judged (O’Reilly, 2007). Women are asked to take on an intensive caregiving role that is “construed as child-centered, expert-guided, emotionally absorbing, labor-intensive, and financially expensive” (Hays, 1996, p.8). This is exactly what the ED social and professional contexts ask of women.

Shame. Blame. Guilt. Embarrassment. We often address these feelings only when they become a barrier to women supporting their children. And while we know women are in pain and struggling, we typically fail to give this sufficient attention. Instead, we arm them with more skills, and therefore, more ownership over their child’s recovery. We do not keep their stories
and experiences at the forefront. We exploit mothers’ love for their child and reinforce the motherhood ideology that requires a “good” mother to intensively caregive. We assign them exhausting responsibilities buttressed by a belief that “it’s what moms are supposed do.”

Marneffe (2009) argues that women are faced with the challenge of integrating “love and loss, togetherness and separateness, and connectedness and autonomy” in themselves and in their relationship with their children (p.83). Women in this study believed that their child’s health depended primarily on them. We amplify and strengthen the love, togetherness, and connectedness, but fail to see women beyond the role of mother to the child. We do not see their whole stories. Doing so closes off a more complete range of possibilities worthy of exploration.

**Tremendous Pressure**

These women are “given the responsibility for deciding what their child eats, how much is eaten, when it is eaten, monitoring all food intake, and generally curtailing physical activity much like the treatment team would do on an inpatient unit” (Rienecke, 2017, p. 70). In addition to these taxing responsibilities is their emotional work.

Women are usually expected to respond appropriately to intense emotional and physical abuse from the child with ED. In my inquiry, and corroborated in other studies (See: Cottee-Lane et al., 2004, p. 172; Fox et al., 2017, p.115), women have sought to understand how to manage and fight the ED by reading literature and seeking online resources.

Fox et al.’s (2017) meta-analysis on the experience of caregiving for a person with an ED labelled the experience as “high stakes.” This meant, according to caregivers, that the potential cost of the ED was very high for the individual with the ED. However, the stakes also are high
for women. Since these stakes put great pressure upon women, there are often “intense negative emotions including distress and fear” (Fox et al., 2017, p.118). The dominant motherhood ideology places these high-stakes responsibilities upon women, who are to save their child at all costs. Yet the costs for women are given scarce attention.

There Are Major Losses

Mothers of children with ED absent themselves from their careers. Their relationships with their partners often deteriorate (Rienecke, 2018). Their relationships with their other children frequently become strained. Their social lives become minimal or non-existent from lack of time and fear of being judged a “bad mother.” Their mental and physical health suffers. I was advised when learning this work to “throw everything you have at the ED so the family can get out of this quickly and return to normal life.” And while I am tempted to state that the losses women experience are temporary, this illness often is long term, and the negative aftereffects of the active ED linger. It is no surprise that women go “numb” (Mila), momentarily retreat for safety (Cara), admit defeat and “stop the fight” (Cordelia), or put on their “Teflon suit” (Yona).

Adrienne is an educated healthcare provider, who has been in this war for about two years. She navigated challenging interactions with service providers. She educated herself, as no one was providing her with enough information to successfully restore her child’s weight. No one told her about the potential for violence. Her relationship with her husband became strained, and she missed out on her other children’s lives. Her social life was lost. Adrienne spoke of her pre-ED sense of self as strong, autonomous, and persistent, but ED shattered that view, leaving her feeling helpless, powerless, and in a constant state of panic and planning. And although
Adrienne’s daughter is recovered, Adrienne’s sense of personal loss remains. Adrienne’s story concludes with her surveying the damage done. She is now tackling the next phase of this war: the clean-up. I will always remember Adrienne’s statement regarding this aftermath, spoken in a tone of quiet exhaustion: “You have to pick up the pieces of what’s broken. Or throw the broken pieces away.”

The constant and pervasive nature of this illness takes a toll on women. Even when treatment has concluded, there is little freedom from the ED. Women move from being engaged in front-line struggles to being sentinels, guarding against the intrusion once again of their child’s illness:

I learned you can never rest easy that it’s over. If you do, that demon can come back in your life again. The stress of living with an eating disorder and the stress of living with some of the conditions that go along with it don’t go away (A mother-participant in Weaver, 2012, p. 413)

Weaver (2012) mentions that women feel they must maintain a “surreptitious watchfulness” (p.415) in case the ED returns. Loeb and Le Grange (2019) state that by training parents to “identify signs and symptoms of AN, they keep relapse at bay” (p.245). The onus is on women to be on guard against the ED, and to be prepared to step in, once again, if it returns.

Hoskins and Lam (2001) recommend that research and practice “should include mothers’ experiences, but with a critical and compassionate eye that attends to how their experiences are interpreted through and re-arranged by the discourses of psychology and modern life” (p. 172).
While their research was conducted over 19 years ago, it remains relevant, and the issues it raises inadequately addressed today.

Mothers are challenged across many child health crises such as cancer, cerebral palsy, and traumatic brain injury (Angold et al., 1998; Cankurtaran Öntaş & Tekindal, 2016; Jordan & Linden, 2013; Kim et al., 2002). They remain inadequately supported in many treatment environments. The ED world is no exception.

The Therapeutic Stance Puts More Pressure on Women

The shift from parental/mother blame to viewing the family/mother as a resource for the child’s recovery from an ED has caused service organizations and service providers to adjust their stance. This paradigm shift has led to a massive handover of responsibility to women/mothers. The service-provider stance changed from one of blame and removing women from caring for their child, to transferring to mothers the complete control over meals and responsibility for reducing ED symptoms. The stance has changed from you are to blame for the illness to you are the one to treat this illness. It is usually called “family-based treatment” or “family-based therapy,” as the “treatment” or “therapy” is supposedly done in and by the family, with the support from a service provider who acts as a “consultant” to the family (Lock & Le Grange, 2013). Given this drastic adjustment, it is necessary to illuminate how services and service providers go about enlisting women in this challenging work, and what additional pressures it adds for mothers.

Assuming EDs are misunderstood in general, service providers educate women through “increasing parental (sic) anxiety” (Lock & Le Grange, 2013) by educating women about the
seriousness of the ED and the challenges of recovery: denial of ED’s severity by the child, refusal to eat the amount required without encouragement, and other impediments to the child’s increased wellbeing. For this reason, women are expected to provide intensive caregiving for their child, and service providers educate women and encourage them in this vital role.

In my own practice as an ED clinician, I recall giving women a sheet of paper listing resources and additional readings. I created packages of literature for them. I encouraged them to connect with an online ED community, since the support I would be giving them at the clinic, one hour a week, might not suffice. For women that inquired about hospital admissions, or more intensive treatment, I would highlight that, ultimately her child would return to the family home, where the ED likely would flourish. Early in treatment, women were taught to learn for themselves how to support their ill child, with the implication that they were mostly on their own.

I told myself that I was empowering these women. I was going to guide them through this process, asking them questions so they could come up with their own answers about how to support their children. They knew their children best. I would teach them some practical strategies (e.g., some parents sleep in their children’s room to prevent them from exercising at night; some parents have removed doors off bathrooms to prevent purging). I would teach them skills to manage the difficult emotions that arise when encouraging someone to eat who refuses to. I thought that I was empowering these women to be intensive caretakers.

When I think back to Adrienne, who commented that the “parent knows best” mentality was not helpful for her and described her desperation to connect with other parents online for
support and recognition, I recalled the reason given to me why the service provider should not provide explicit instructions. This stance “allows [parents/mothers] to rely largely on themselves more than the therapist or treatment team, thus building confidence” (Rienecke, 2017, p.71). These women were saying that they needed more support and more connections, yet the therapeutic stance was to encourage autonomy. The reality became that these women navigated this challenging illness, full of uncertainty and high risk, substantially alone.

Women want to know more about the journey they are about to embark on, so much so that many request a “road map.” In Wufong et al. (2019), parents did feel that the family-based treatment initially gave them a treatment “road map,” but in the long term it increased their feelings of blame when the treatment did not reach successful conclusions. A family presented in Conti et al. (2017) stated that the family-based intervention felt like “somebody else’s roadmap” whereby the rigidity of the family-based intervention was more harmful than helpful. In Conti et al.’s (2017) study, the family members highlighted the lack of opportunity to express their worries. The focus remains on weight restoration and symptom reduction. This led to a “number of therapeutically important family stories” to become “hidden and unaddressed” (p.421).

Each of the women in this inquiry had unique histories and situations. There is no single roadmap available to meet their specific circumstances. Rather, communicating openly about the realities and challenges of treatment, partnering with women to establish the course of action, and finding creative ways to increase support, may be the most effective guidelines.

In order to be successful, women “must feel confident in their interactions with their child and with the eating disorder. The therapist works to *empower* [emphasis added] parents by
putting them in charge of the process and communicating to them that the therapist has confidence in their ability to beat the eating disorder” (Rienecke, 2017, p.71). The women in this inquiry did not feel empowered. They felt pressured to get their child to eat, to interrupt symptoms, and to increase the child’s weight, and they felt to blame if they failed.

Riger (1993), a community psychologist, highlights that psychological mental health interventions tend to emphasize separation and autonomy over relationality, that a “mature adult in psychological research is characterized by mastery, control, and separation, rather than interdependence or relatedness” (p.285). Women are placed in positions that demand that they control not only the ED behaviours, but their own reactions to the ED. They are pressured to make decisions by themselves and not rely too heavily on outside help.

A major health discourse in North America gives individuals responsibility for maintaining and improving many aspects of their own health (Cheek, 2008). Self-care is widely endorsed as beneficial practice, and echoed in ED literature (Patel et al., 2014, p. 594). Self-care in the ED context is promoted as important for women in order to preserve and restore their wellness, but also to “ultimately aid in a child’s recovery because parents will be energized, confident, and better able to participate in recovery” (Patel et al., 2014, p. 594). Yet, women face multiple barriers to self-care, such as the cost for individual therapists, the loss of their social group, strained connection with their partners, and the challenge of allocating time for self-care. The onus is on women not only to care for their children, but also to manage and plan for their own self-care. Many women in this study recognized the importance of self-care but confronted the logistical and emotional challenges of doing so.
It is important to recognize the limits of self-care. It is an individual responsibility. It puts the onus on women to manage *themselves* in order to be more effective for their children. It diverts attention from looking at ways systems of care could better support women. While health ecological frameworks stress the importance of focusing on multiple levels, health and wellness advancements remain focused on individuals and ways to increase their knowledge, alter their viewpoints, and enhance their skills (Golden & Earp, 2012). Attention to self-care is important, but a community of care, partnering, and collaborating to develop resources is also needed.

I believe that what would empower women would be to listen to their experiences and then find ways to respond both as service providers and service developers. We need to examine how the current stance of empowerment may diminish women’s confidence and well-being. There needs to be an understanding of mothers’ personal experiences, the environments in which they are interacting, and the societal expectations placed upon women and mothers. We need to address the tension between their employment responsibilities and their child-caring responsibilities, the burden of caring for multiple individuals (the mother herself included), and the expectation of little additional support or resources.

*Valuing the Role, Not the Person*

How do we view these women? Do we value them? Or do we value what they are doing for their children? If I step back and reflect, I believe it was their actions that I valued, not them. I was often so focused on the specified treatment interventions that the woman was or was not doing, and the wellness of her child, that I failed to see her as a person. I also valued her
relationship with her child over all else. Notably absent were concerns about the women themselves.

If I asked these women whom they valued more, themselves or their children, I am sure that most, perhaps all, would prioritize the well-being of their children. It is for this reason that I think that women tend to scrutinize their own caregiving practices, viewing themselves as doing motherhood “wrong,” and blaming themselves for the ED onset and progression (Hoskins & Lam, 2001). Women stated in this inquiry that the treatment was not family therapy, but family-administered therapy, specifically, mother-administered therapy.

In LaMarre and Rice’s (2020) work on “recovery assemblage,” they highlight not only the experiences of the individuals diagnosed, but of the carers. Centered in their study is an “at any cost” mentality: those supporting someone with an ED often push aside their own emotional needs in order to care for their loved one. As one mother stated:

But, from a parent perspective, we didn’t have time to do our own self-care. I should have been seeing someone. I was too busy seeing doctors and psychiatrists and stuff with my daughter, because it was family-based treatment. And don’t get me wrong, I’m overjoyed that my daughter’s doing well, and she’s alive, but the thing is, is at what price? (pp.11-12)

I am reminded of Mila, who stated she would pour everything she could into the care of her daughter at great loss to herself; in fact, she had already begun to suffer physically from her unattended autoimmune disease and had put her own career on hold. Mila feels she may have saved her daughter, but what has been the cost to her wellbeing in doing so?
Caregiving often is free labour that falls heavily on women. Family-based interventions are cost effective from an institutional viewpoint (Lock et al., 2008). Wufong et al. (2019) discuss how discourses of “good” parenting/mothering obscure both the “burden on these parents (sic) and families and the institutional positioning of MFT/FBT (family-based intervention) as a cost-effective treatment for adolescent AN” (p.9). As one mother in this study remarked, “The Maudsley Method (another name for the family-based intervention) seemed to me, when I was feeling really negative, […] a cheap way out for the government to treat my child, tell us to deal with it” (p.9). Hughes et al. (2020) reported in their study of 145 parents (104 of which were biological mothers) that 51% of parents needed more support through the treatment process as their own mental health deteriorated. If women were equally valued in the treatment setting, their struggles would be given adequate attention. Does the dominant family-based model risk “…under-acknowledging and underestimating emotional and material cost on parents (sic) who are asked to take responsibility for re-feeding their child in the early phases” (Aradas et al., 2019, p. 12)?

Women in this inquiry noted that they were not seen in clinical settings. Some said that they were not contacted by a therapist, that no one really asked how they were doing or what they needed to manage their burdens. And, I will admit, when I did check in on women’s mental health, it was under the guise that I needed the mother to be well to care for her child. If the mother could not do this work, I feared the revolving door of hospitalizations for the child (Aradas et al., 2019, p. 4). LaMarre and Rice (2020) state that “persons in ED recovery, and their
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caregivers continue to exist within, and in various relationships with, people and systems that constrain options for care and recovery for both of those in recovery and caregivers” (p.14).

The Need to Share and Partner More Effectively

ED represents not just a long, arduous, high-stakes journey, but also a very lonely one. It is no surprise that women in this inquiry often spoke of the loneliness of this journey. The support these women received was not balanced with the amount of responsibility that they assumed. The recommended FBT treatment model has not been designed with considerations of the pressures women face or their wellness in mind. FBT service providers may in fact discourage women’s discussions of their personal feelings in order to remain focused on the task of symptom interruption. Dring (2018) argued that this may make it challenging for such discussions to occur later on when therapy is concluding.

Service providers are to “insist that parents (sic) remain relentless until they are convinced that the patient clearly understands that she will not be able to return to the anorexic behaviours while a part of the parents’ household” (Lock & Le Grange, 2013, p. 126). How long are these women expected to remain “relentless”? Women in this inquiry had been engaged in intensive caregiving anywhere from two months to two years.

This illness is rife with challenges, and women are in a position of having to navigate this uncertainty and anxiety for potentially long periods of time. As one mother in McArdle (2019, p.407) stated: “Foolishly, I thought it would be a quick fix, that we wouldn’t be sitting here two years later.” Additionally, in one study, 40% of individuals who participated in FBT had “considerable ongoing psychological and psychiatric problems” (Lock et al., 2006, p. 672).
Clinicians are aware of the long duration of this illness and have acknowledged that coping with this treatment can be traumatic (Aradas et al., 2019; Astrachan-Fletcher et al., 2018).

I want to be explicit that this is not a fault of service providers as they themselves struggle to negotiate their role and their reactions to family-based interventions (Aradas et al., 2019). However, if it is an acknowledged ED reality that many women will be living with for a long period of time, we need to consider ways to partner with these women.

There is a dire need to look beyond how to utilize and train women to be intensive caregivers. More focus is needed on how we can create supports and resources that focus on the wellness of all individuals experiencing this illness. Conti et al. (2017) ask, “Does the end justify the means? Does therapy have to be so painful? Does it matter that therapy can have detrimental effects in the process of facilitating weight gain?” (p. 423). There is room for lots of flexibility in family-based interventions, but I caution that we have forgotten or ignored the perspectives of women.

Where Do We Go from Here?

“Hi Jen, We will do everything that we possibly can to try to get her to eat when she is supposed to today. [...] Things are just so much worse at the moment. [...] There is so much chaos, yelling, screaming right now. Our sleep is suffering. She is not getting connected sleep for more than a couple of hours at a time. [...] We could not get her eating her dinner until 12:45am. At one point I was standing in the kitchen crying, telling her to come eat and she continued her [exercising]. I had to go to bed at 1:45, I was so tired. It is taking a toll on my physical health. The stress, worry. Yesterday my nose starting bleeding while I was desperately trying to get her to eat her breakfast at 4 in the afternoon. [...] We have lost all control.” (With permission, an email from a mother, January 2021).
It has now been two years since I wrote my introduction to this thesis. In my private practice, I continue to maintain contact with families who have a child diagnosed with an ED. However, what I have to offer is not enough, and more intensive services have long waitlists. The above mother has been in the position of intensive caregiving for almost a year. The pressure I inadvertently have placed upon women in similar circumstances is not only unreasonable, but also damaging. I have little to offer these struggling women and their families. I continue to provide education, practical suggestions, emotional support, and skills-based education. But it is not enough.

Research focused on these mothers and their well-being is minimal. An imperative from this research is to improve ways of helping women and other ED caregivers. We know that caregiving for a child with an ED is a heavy burden and typically contributes to poor mental health and low quality of life for mothers (Kyriacou et al., 2008; Martin et al., 2013; Ohara et al., 2016). Inevitably family living deteriorates. What is being asked of mothers is unreasonable and unsustainable.

It is important to note that the challenges and circumstances that arose from this study cannot be addressed by individual clinicians. There is a dire need for collective thinking and developing studies that test out new approaches to support women, starting with ideas highlighted below.

**Supporting Mothers**

Support comes in many forms: emotional, educational, and practical/instrumental. Women are usually the prime family caregivers. Currently supports are not based on examination
of the unique stressors these women face, from leaving their careers, having minimal contact with their social networks, and living up to the often unspoken, but prevalent expectations of mothering ideology (Arendell, 2000; Rich, 1995).

We have begun to explore caregivers’ experiences and how to better help them support their loved ones while keeping themselves well (Goodier et al., 2014; Lafrance Robinson et al., 2015; Treasure et al., 2015; Truttmann et al., 2020). However, discussions have focused on psychological and skill-based interventions, to be learned in structured sessions. We need to explore and create a broader range of practical and accessible supports and resources for these women in their caregiving role.

**Empowerment**

Empowerment is a challenging concept. It means different things to different people and in different contexts, but is “easy to define in its absence: powerlessness, real or imagined; learned helplessness; alienation; loss of a sense of control over one’s own life” (Rappapon, 1984, p. 3). Disempowerment, not empowerment, is what women have described feeling in this investigation.

Descriptions of how clinicians in the FBT approach are supposed to *empower* parents (*mothers*), through raising their anxiety about the illness, psychoeducation, and encouraging parental control, is helping to create *disempowered* states for women. ED research emphasizes the importance of “parental (mothers) empowerment,” but little idea of what empowerment means for these women or how to cultivate it.
Raising anxiety and adding fear to parents, and then asking them to make great sacrifices, is not empowering. We need to speak with ED caregivers to understand and define what empowerment is, and what would actually empower women and other caregivers.

**Expanding Concepts of Helping and Sharing the Burden Over Time**

“We have to keep doing what we’re doing. This is all I have to offer at this time. This is the nature of EDs. Maybe you need a treatment break.” These are all phrases I have spoken to mothers at some point in treatment. I would encourage continued monitoring, give advice on higher-calorie meals and ways to alter their homes to interrupt symptoms more effectively, and teach skills and ways of interacting when their child was in distress. But it was seldom enough, especially when the struggles went on for months and even years.

We need to expand our ways of helping beyond the clinical interventions that currently put excessive pressure on mothers. It is insufficient to think in terms of tasks mothers should implement, or ways women can change themselves and their interactions to support their children. We need to learn how to provide longer-term help and how to foster professional and community sharing of the burden with these women and families. It must not continue to be solely an individual responsibility.

Self-help and informal support networks, such as private social media groups and F.E.A.S.T (F.E.A.S.T. - Support and resources for families affected by eating disorders, 2021) have been created to support caregivers who have a child with an ED. Also needed are expansion and development of such networks and an examination of their nature, requirements, and efficacy. Other examples of communal support should be investigated, such as the Swedish
model of contact persons/families for mothers and children. Contact person/families allow both parents (mothers) and kids to initiate contact and provide a range of supports including respite (Andersson, 2002).

**Considerations for Frontline Practitioners**

I would be remiss to not discuss my own learnings from this inquiry that have impacted my clinical practice. I continue to work primarily with mothers who have a child with an ED. I am more cognizant of my own inappropriate biases and expectations that seep out into my clinical practice. Questions that guide me in my practice, and that reorient me to women’s experiences are: Have I allowed space in this session for women to express the challenges and limitations they face? Have I imposed recommendations without giving adequate attention to the complexity of their lives and circumstances? Am I supporting the idea of intensive mothering by placing such demands on women? What language am I using in practice and clinical documentation and what impact does this language have? Is this empowering language, or pressuring language? How can I create a balance between the child’s wellness while sustaining the physical and mental health of women and caregivers?

Balance does remain a challenge in my practice. While I may not have the current knowledge on what an appropriate balance is, exploring how to balance multiple needs is necessary. At this time, it is unclear the best way to give support to women and caregivers in this context. It is worthwhile to explore supports beyond psychological interventions for women and look at ways to create or integrate structural supports, such as opportunities for respite and connecting women with others who have experienced this challenging illness.
EDs are often long-term illnesses requiring ongoing caregiving. I question why this responsibility falls so lopsidedly on mothers and families, given our awareness of the intensity and duration of the illness. We must begin to investigate ways to share the burden with women and families over time and move beyond individual responsibility. To do so, we need to discuss ways to mitigate the individualistic predisposition reflected in our treatment approaches. We need to look broadly and become more creative in thinking about what could support women and their families effectively, both immediately and over time.

We cannot ask women to continue in a state of toxic, individualized perseverance with inadequate support. They are struggling, they are suffering, and they are putting great responsibility upon themselves for their child’s outcomes. The ED field has made many positive shifts and has begun to recognize the vital importance of families in the care for their loved ones, but we have inadequately addressed the collateral consequences of their caregiving. We still have much to learn from women and families, and much work to do to support them.
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Mothers: Do you have a story to tell?

Mothers are typically the prime caregiver for their child. When a child is diagnosed with an eating disorder, research shows that mothers are typically taking on a majority or the extra, and intensive, caregiving needed for their child.

Currently, we know very little about the lives of mothers who have a child diagnosed with an eating disorder. Research that does look at mothers while a child who is diagnosed with an ED takes on either a punitive and judgemental lens or is based on assumptions of their lived realities and expectations.

Your story is important, and it is a story that only you can tell. I would like to hear your story of what it is or has been like to be a mother to a child diagnosed with an eating disorder. Should you choose to participate in this research, you will be contributing to knowledge on the lived realities that mothers have when their child is diagnosed with an eating disorder. Your participants can help improve services and support for other mothers who have a child diagnosed with an eating disorder.

Please note that confidentiality is ensured. Should you elect to participate in this study it will not impact your services at the Eating Disorder Program. Clinicians will not know of your participation. Additionally, should you choose to participate, interviews are conducted in a at a time and place that is convenient for you.
Below, you are agreeing only to hear more about the study. You may still decline to participate after speaking with the researcher, Jennifer Scarborough.

If you are agreeable to hearing more about the study, please provide the following information, and I will be in touch with you:

Name: _____________________________

Phone Number: ______________________

Best day/time to call:____________________________

E-mail: ___________________________

If you would like to contact the researcher, please Email Jennifer at: jscarborough@wlu.ca.

Jennifer is a doctoral candidate at Wilfrid Laurier University.

Regardless of if you have filled out the information in this paper, please put this paper in the envelope provided to ensure confidentiality.

This study has been ethically approved at CMHA and WLU. Research Ethics Board File # 5932
Appendix B: Consent Form

Mothers of Children with Eating Disorders
Wilfrid Laurier University
Consent Form
(Oral Story)
You are one of ten mothers invited to participate in an interview as part of a research study. The purpose of this study is to learn about the everyday lives and service experiences of mothers who have or had, a child diagnosed with an eating disorder (ED).

The objectives of this study are:

- to personalize mothers’ stories,
- to gain an understanding of what it is like to be a mother of a child diagnosed with an ED,
- to share mothers’ stories with other mothers of children diagnosed with an ED and service providers to help ED agencies improve their services

In this study you will be involved in the following:

If you agree to participate in the study, the interviewer will ask you to tell the story of being a mother to a child diagnosed with an eating disorder. This will take place over the course of 2-3 interviews. These interviews will be audio taped. Each meeting you have with the interviewer may last about 1.5 hours. You do not have to talk about anything you are uncomfortable with if you do not wish to. And you can stop the interview or withdraw from the study at any time.

Each interview will be transcribed. After all interviews are completed, the research (Jennifer) will construct a summary of your stories. You will be given a copy of your story to
review. You can then check for accuracy and have any additions, subtractions, or other changes made to your story.

We may want to quote some of the information you share with us in our research reports. By including quotes in our reports, we will be able to better describe the day-to-day lives of mothers who have a child diagnosed with an eating disorder. If so, this will be done in a fashion that does not identify you in any way. You are also protected by the fact that no one besides the research team will know that you are in the study. The Eating Disorder Program will not know whether or not you have agreed to take part in the study. Regardless, if you would like any quotes or information removed from the summary, this will be done.

_______Participant’s Initials

Your anonymous story may then be shared with a focus group of service providers at the Eating Disorder Program, and a focus group of mothers who have a child diagnosed with an eating disorder. The focus groups are reading two stories of mothers of children who have/had an eating disorder and getting their impressions and thoughts. You may choose to not have your story shared. Before stories are shared, you will receive a copy of your story in order to check for any information that may be identifying.

Confidentiality

Whether or not you agree to take part in the study, your services at the Eating Disorders Program will not be affected. If you withdraw from the study before we are done collecting
information, you can still let us use the information you have shared with us, or you can choose to have your information given back to you or destroyed.

We would like to audiotape the interview to make sure all of the information you give us is accurately noted. Interview tapes will be kept in a locked cabinet at the university. Only Research Team members will have access to these tapes. Interview tapes will be erased after they have been transcribed.

All information you share with the researcher will be anonymized. The information will not be used to identify you or your family in any way. Once we have finished the interview and you have received a copy of it, we will remove any identifying information (such as your name, where you live, the number of kids you have, and so on) from our record of the interview.

Your participation in the interview will be kept confidential. However, please be aware that if you tell me about any current mistreatment of children, I am required by law to report this information to the Children’s Aid Society.

**Risks**

Participating in the interview may be helpful in letting you express your thoughts and feelings. However, if you find any of the questions upsetting and need someone to talk to, or if you have any questions about the study itself, you can call any of the numbers we have provided. These phone numbers are listed on the Contact Information Sheet. For your information, this research study has been reviewed and approved by the Research Ethics Board at Wilfrid Laurier University.
To thank you for the time you spend talking with the interviewer.

____ Participant’s Initials

I have read and understand the information given to me. I have received a copy of this form. I agree to participate in an interview that will be audio-taped.

___ YES  ___ NO

I would like a copy of the information I share in these interviews sent to me.

___ YES  ___ NO

I understand that I will have an opportunity to review any quotations that may be used in the narrative summary and accept or decline their use upon review.

___ YES  ___ NO

I would like to be sent information about the study’s overall findings

___ YES  ___ NO
Participant’s Signature  
Date

Interviewer’s Signature  
Date

Participant Contact Information (if you’d like a copy of transcripts)

Name: _________________________________________
Address:________________________________________
Telephone:______________________________________
Alternate Phone Number: _________________________
Email: _________________________________________
Contact Information Sheet

If you need someone to talk to about your feelings, you can call:

TorchLight
Here 24/7
Mental Health Helpline
Telecare Cambridge

If you have any questions about the study, you can call/e-mail:

Jennifer Scarborough, Researcher
Dr. Gary Cameron, Supervisor

If you have any questions about the way you were treated by researchers, you can call:

University Research Ethics Board
Wilfrid Laurier University

Jennifer Scarborough, Principal Researcher, Wilfrid Laurier University, Faculty of Social Work
Dr. Gary Cameron, Supervisor, Wilfrid Laurier University, Faculty of Social Work
Appendix C: Interview Guide - Mothers’ Narratives

Introduction to the Narrative Interview

I am meeting with you today to hear your story. I hope that you will share important things which have taken place in your life. There are no incorrect ways discuss these topics. Only what you think and feel is important.

Mothers who have a child with an ED rarely have a space to tell their own story and version of what is happening in their lives. These stories are rarely spoken in clinical settings. Generally, we often tend to hear what other professionals in the ED field think. I’m hoping to provide some balance and understanding to the realities you face and the unique experiences you have encountered. I want to hear your story simply the way you wish to tell it.

You get to decide what we talk about. If there is something you wish to not have in your story, that is respected. You do not have to tell me any more than what you want to talk about. If at any time during your story telling you want to talk about something else or stop the conversation, that is also okay.

Beginning the Interview

I want you to imagine that someone (in particular, me) will be making a movie about your life during the time your child had an ED. You get to decide what goes into this story. You
want to make sure that the things you see as important to you are included in this story, and that this story is told the way you want it to be.

Do you have any questions before we start?

The story can start at any point. We can begin with a time or any event that happened which you feel is important. Where would you like to start?

- Where would the story begin?
- What do you want to talk about first?
- What happened?
- Why is this important to your story?
- How did this impact on your life?
- What kind of time was this?
- What do you want to make sure I understand about this part of your story?

Is there anything else you want included in your story, or anything that was missed?

Anything you want to elaborate on or clarify?

(Repeat the cycle until the whole story is told)

**Additional Topic Guide**

- Before the ED
- After the ED (if applicable)
• Hopes and fears
• Good and Bad
• Thoughts & Feelings
• Beliefs
• Aspirations
• Health & well-being
• Interests
• Work and recreation
• Home life
• Relationships
• Sources of comfort
• Sources of stress
• Other supports (community, social services)
• Fulfillment
• Growth

**Ending the Interview**

Thank you for sharing your story with me. What I will do now is listen to your story and familiarize myself with it. You and I will meet again on (date), and I may ask for further information on things you’ve mentioned. We will follow the same type of structure we did today.