CAN MEMOIR CONTRIBUTE TO A MORE COLLABORATIVE APPROACH TO TREATING EATING DISORDERS THAT RESPECTS AND INCLUDES THE FAMILY?

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A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF EDUCATION

in

THE FACULTY OF GRADUATE AND POSTDOCTORAL STUDIES (Educational Policy and Leadership)

THE UNIVERSITY OF BRITISH COLUMBIA

(Vancouver)

March 2015

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ABSTRACT

Eating disorders are on the rise among adolescents in North America along with an increase in mortality rates due to complications associated with the disorder. Eating disorders also have a profound effect on families. Feelings of anxiety and depression, stress, and burnout are commonly associated with caring for an adolescent with an eating disorder. In addition to this, many families feel isolated and blamed by health-care professionals and receive little support, collaboration, or education about the disorder. Simultaneously, health-care professionals also struggle with feelings of frustration, stress, burnout, and judgmental attitudes towards families due to the lack of knowledge and understanding of eating disorders. There are gaps in the knowledge of health-care professionals, both in terms of understanding the disorder, and supporting patients and families of adolescents with eating disorders.

This dissertation endeavoured to fill this gap. My main research question was “what contributions arise from writing a memoir about the impact on a family of a female adolescent with an eating disorder and the family’s encounters with health-care professionals?” My sub-questions were: a) “what is the outcome of sharing that memoir with health-care professionals?” and b) “how can this memoir contribute to a collaborative approach to treating eating disorders that respects and includes the family?”

A qualitative study encompassing a two part design was used. Part one comprised the creation of a memoir of my journey through my daughter’s experience of an eating disorder from my perspectives as a mother, my interactions with health-care professionals, and my role as a health-care professional caring for adolescents with
eating disorders. Part two involved the reading of the memoir by seven participants, all pediatric nurses whose practice included the care of adolescents with eating disorders. Through an online focus group, participants responded to pre-determined questions and to each others answers. Through this study, the value of a memoir was apparent as a way for nurses to reflect on their caring practice and to identify barriers to providing effective care. The memoir proved to be a catalyst for bringing additional resources to support nurses' caring practice.
PREFACE

This research has been approved by UBC’s Behavioural Research Ethics Board (H13-02828).

A version of my memoir (Chapter 4) was published in my book:

My daughter Melody has given permission to have her name and story shared in this dissertation.
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ACKNOWLEDGEMENTS

I want to acknowledge the support of my committee. Dr. Carl Leggo, as my co-advisor you provided the encouragement, wisdom, and direction throughout the preparation and completion of this dissertation. Thank you from the bottom of my heart. Dr. Shauna Butterwick, as co-advisor, your expertise, direction, honesty, and patience are what I needed to grow and develop as a researcher. Without you I wouldn’t have finished this dissertation. Dr. Barb Pesut, your expertise, support, and guidance made the research process a rewarding experience. I also want to acknowledge the support of the Director of the UBC Okanagan School of Nursing, Dr. Tricia Marck, who supported a sabbatical leave to allow me the time to complete this dissertation. And finally, I wish to acknowledge Dr. Gerda Wever from “The Write Room” for her expertise in editing this dissertation.
DEDICATION

I lovingly dedicate this dissertation to my daughters Bridget, Simone, Danielle, Melody, and Jamie. I would not have finished this without your support and love. You listened patiently as I discussed study results, or lamented over the never ending chapter revisions. You were there for me when I hit the “brick wall” and encouraged me to keep going. You reminded me that I was making a difference and that this work was important. You have always made me feel like I can do anything I put my mind to. Well guess what? I DID IT and I want to share it with you. Let’s go celebrate, girls!

I also dedicate this dissertation to my precious grandchildren, Emily, Theo, Evan, Everett, and Max. You gave me such joy during the long months of writing. You kept the smile on my face because you make every day wonderful and exciting and new. Always remember that you can do anything you put your mind to and Nana will be right at your side.
CHAPTER ONE: INTRODUCTION

Eating disorders are on the increase among adolescents in North America (Fichter, Quadflieg & Hedlung, 2006). Statistics Canada (2013) states that eating disorders affect between 0.3% and 1% of adolescents (over 90% are female) which is higher than in previous years. These statistics are alarming as a study by Fichter et al. (2006) revealed that an estimated 5% to 20% die from complications related to eating disorders. Offord, Turner, and Cooper (2006) believe that eating disorders are a serious condition with mortality rates estimated to exceed all other adolescent psychiatric disorders, including depression.

Diagnostic criteria for eating disorders such as anorexia nervosa include: refusal to maintain a minimally normal body weight (body weight less than 85% of that expected) or failure to make expected weight gain during growth periods; intense fear of gaining weight or becoming fat; a distorted view of one’s body weight or shape, unnecessary influence on self-evaluation, or denial of the seriousness of low body weight; and amenorrhea—absence of at least three consecutive menstrual cycles (The American Psychiatric Association, DSM-V, 2013). A study by Kaye (as cited in Le Grange & Lock, 2011) found that persons with an eating disorder close to death will show you on their bodies where they feel they need to lose weight. Fairburn and Harrison (2003) state that persons with an eating disorder over-evaluate their shape and weight. Whereas the majority of persons assess themselves on the basis of their

\[ \text{In this dissertation I use persons, daughter, patient, and adolescent when referring to persons with eating disorders. When discussing someone with an eating disorder in general I use “person.” In the context of families I use “daughter” or “adolescent,” and in the context of hospitalization and nursing care I use “patient.”} \]
perceived performance in various domains such as relationships, work, parenting, and sporting prowess, persons with an eating disorder judge their self-worth largely, or even exclusively, in terms of their shape and weight and their ability to control them.

Although eating disorders have gained much attention over the last several decades the etiology remains unclear and somewhat contradictory as discussed by Mazzeo and Bulik (2009). Environmental risk factors have received the bulk of research and clinical attention, according to the authors, in particular, sociocultural influences, such as unrealistically thin media images have been hypothesized to promote disordered eating and body dissatisfaction. And yet, it is clear that although virtually all women are exposed to these sociocultural influences, only a very small proportion develop clinical eating disorders. The University of Maryland Medical Center (2011) asserts that there is no single cause for eating disorders, and although concerns about weight and body shape play a role in all eating disorders, the actual cause of these disorders appear to result from many factors, including cultural and family pressures and emotional and personality disorders. Conversely, Kaye (as cited in Le Grange & Lock, 2011) believes that genetic factors play a key role in the development of eating disorders. Family studies of persons with eating disorders have consistently found a higher lifetime prevalence of eating disorders among relatives of those with eating disorders than those among relatives of control participants. Polivy and Herman (2002) researched the long held belief that family dynamics is the major contributor in the development of eating disorders. Past case reports and studies of family interaction identified eating-disordered families as enmeshed, intrusive, hostile, and negating of the patient’s emotional needs. In contrast, a study conducted by Swinbourne and Touyz
(2007) discovered a correlation between anxiety disorders and eating disorders. The research revealed that often anxiety disorders pre-date eating disorders, leading to a suggestion that early onset anxiety may predispose persons to developing an eating disorder. In brief, the literature shows that there is no assured understanding of the cause of eating disorders, thus making it difficult to develop effective treatment protocols as discussed by the National Eating Disorders Association (NEDA, 2014). NEDA states that a variety of treatment options are utilized for persons with eating disorders including medication, psychotherapy or counseling; however, there is not one standard treatment protocol as the exact treatment needs and response to treatment of each person varies.

**Background and Interest**

Along with the confusion about its etiology and the lack of agreement about effective treatment protocols, eating disorders also have a profound effect on families. Although there is some documentation in the literature, according to Hillege, Beale, and McMaster (2006) much more research is needed on this topic. They noted that what has been written is often from the perspective of persons with an eating disorder and their therapists; these studies include little mention of parents or families. What little is mentioned about parents, particularly mothers, is mostly negative and concentrates on their role in the underlying causation of the illness. Despite the lack of documentation, eating disorders present many challenges to families. A study conducted by De LA Rie, Van furth, De Koning, Noordenbos, and Donker (2005) utilized both quantitative and

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2 In this dissertation, I use parents and families interchangeably, depending on the context.
qualitative methods to consider the impact of eating disorders on various areas of life domains and on the relationship with the eating disorder patient and the need for professional support. The outcome of the study, which involved 40 families of eating disordered patients, was that the quality of life for these families was poor and they reported less quality of life in terms of energy level and fatigue, anxiety, depression, loss of behavioural or emotional control, and psychological well-being. This is compounded by negative experiences between families and health-care professionals. A cross-sectional study design was used by Kyriacou, Treasure, and Schmidt (2008) to assess family strains and psychological distress. The study included 151 mothers and fathers of adolescents with eating disorders. The findings revealed that family complaints include: lack of information from health-care professionals, stressful experiences in obtaining help through health services, feeling excluded or even blamed for the illness, and poor social support and understanding of the disorder. This is disturbing according to Honey and Halse (2005), particularly in light of the fact that families are often viewed as important to treatment outcomes for their adolescent.

The aim of the study carried out by Haigh and Treasure (2003) was to develop and test an instrument that can be used to assess the needs of 28 families of persons with an eating disorder. A pilot test of the instrument revealed that families’ needs are often overlooked, in particular their need for information regarding treatment options, prognosis, and future treatment plans as well as information on coping strategies when caring for an adolescent with an eating disorder. A qualitative study conducted by Cottee-Lane, Pistrang, and Bryant-Waugh (2004) examined the experience of parents who had an adolescent with an eating disorder. Semi-structured interviews were
carried out with 11 family members. The findings revealed that families placed importance on being acknowledged by health-care professionals as an integral part of and resource for their adolescent’s recovery and treatment process. Families also voiced that an acknowledgement that families are a resource and help, rather than a hindrance, would have a positive effect in the recovery of the adolescent.

As a nursing instructor and curriculum committee member at the University of British Columbia Okanagan (UBCO), I know that eating disorders are very briefly discussed within the mental health theory section of the UBCO nursing program in which several other mental illnesses are discussed. For this reason, our registered nurses often struggle in providing best care practices for adolescents with this debilitating disorder as well as meeting the needs of the families (B. McGrath, RN, PCC pediatrics, personal communication, June 24, 2013). In the pediatric unit where I work as a registered nurse, we have had discussions over the years about our patients, mostly female adolescents, with eating disorders and the central causes of the disorder. From our collective observations on the unit, we determined that many of the mothers appear cold, angry, and distant when visiting their hospitalized adolescent daughters. We concluded that the mothers were trying to control their daughters and the daughters were rebelling against the control. We believed that eating disorders were the result of an abnormal mother/daughter relationship, and, therefore, as nurses we had to fix what these mothers had broken. This ‘us against them’ attitude led several nurses into wary and guarded relationships with the mothers of these adolescents. I have since determined that reaching hasty conclusions to complex problems without seeking accurate information or literature can be detrimental.
I came to this realization when my daughter developed an eating disorder. I recognized I was one of “those mothers,” and I began to reassess my preconceived notions about these mothers. What I previously considered to be a cold and uncaring stance, I now identified as fear, pain, exhaustion, and utter isolation. I appreciated that these mothers most likely love their daughters as much as I love mine. I conceded that the lack of knowledge and understanding of eating disorders creates a toxic hospital environment that stigmatizes and ostracizes families. This experience has taught me that families must not only be included and informed about the care of their adolescent, but also supported by health-care professionals rather than blamed and judged for the disorder.

**Purpose and Goal of the Study**

There were several goals for the study. The first goal was to write a first person account, in the form of a memoir, in which to explore the negative impacts of the illness on families as well as the impact of health-care professionals’ lack of knowledge and the tendency to blame and judge families. Second, the purpose was to examine the responses of health-care professionals to the memoir by sharing my memoir with my nursing peers and documenting their responses through an online discussion forum. Third, the goal was to further health-care professionals’ understanding of the importance of a collaborative and supportive approach involving families of adolescents suffering with an eating disorder and to ultimately improve recovery rates. Overall my goal is that through this research, health-care professionals would learn about the impact on families and the importance of including and informing families about the care of their adolescent, and to be supportive, rather than blaming and judging them.
**Research Questions**

My main research question was: What contributions arise from writing a memoir about the impact on a family of a female adolescent with an eating disorder and the family’s encounters with health-care professionals? My sub-questions were:

a. What is the outcome of sharing that memoir with health-care professionals?

b. How can this memoir contribute to a collaborative approach to treating eating disorders that respects and includes the family?

**Research Design**

This qualitative study encompassed two parts. Part one comprised the writing of a ‘memoir’ which, from my perspective as a mother, put into words my journey through my daughter’s experience with an eating disorder, my interactions with health-care professionals, and my role as a health-care professional caring for adolescents with eating disorders. It was hoped that my unique perspective would shed light on how experiences with health-care professionals affect families and ultimately impact the recovery of adolescents with eating disorders. My memoir was part of a collection of essays previously published in my book A Melody of Hope: Surviving Your Daughter’s Eating Disorder (2011). My story in that book was revised to include further reflection regarding my role as a nurse caring for patients with eating disorders, and my interactions as a colleague with health-care professionals. According to Armstrong (2006), memoir not only tells an autobiographical story, it is also a reflective, thoughtful form that requires the writer to reach beneath and beyond her own story in order to discover, analyze, understand, and communicate a meaning beyond and beneath the events in the story. It is a process of discovery, a journey towards new understanding.
Conway (1998) states that every autobiographer hopes others learn from her or his life and become convinced to take up some important cause, follow a new spiritual path, be aware of particular hazards, and develop a new moral sense.

Part two involved an online focus group. A group of health-care professionals who were my colleagues read my memoir and responded to predetermined open-ended questions. According to Oringderff (2004) online focus groups are an emerging qualitative method that enables researchers to capture primary data. The aim of a study by Kenny (2005) considered whether active engagement and group interaction could be captured in an online environment. Thirty-eight Australian nurses participated in an online focus group. The study findings revealed the experience of conducting an online focus group was a positive one. Advantages such as cost savings and convenience for both researcher and participants were identified. Participants could engage in discussions as their schedules permitted. This study demonstrated that participants could be actively engaged and that group interaction could be achieved to collect richly detailed research data. As well, online focus groups provided anonymity for topics that may be complex, embarrassing or sensitive.

My colleagues work on a rotating shift schedule and hence it was difficult to schedule traditional face-to-face group discussions, therefore I utilized the online focus group method. I drew from a convenience sample that included my existing network of nurse colleagues in a hospital pediatric unit where I am employed in British Columbia, Canada. The registered nurses had at least one year post registrant experience caring for patients with eating disorders. The registered nurses were asked to voluntarily
participate in reading a memoir and then answer four questions related to the memoir in an online group forum.

The data was then analyzed to identify the themes that emerged. A more detailed discussion of the methods and procedures for the study’s design, sampling, data collection, and data analysis is provided in Chapter 4.

**Significance of the Study**

The study is significant as it adds to the developing body of knowledge about eating disorders, specifically its impact on families. The study also contributes to knowledge of how the lack of knowledge and judgmental and blaming response of health-care professionals to patients with eating disorders and their families has a profound impact and actually undermines recovery. The study contributes to understanding the importance of supporting patients and families of adolescents with eating disorders, and the benefits of a collaborative care approach. The study is unique in that it included the writing of a personal memoir and the response to that memoir by health-care professionals thus contributing to a growing appreciation of the power of narrative, memoir and story as key to supporting parents, particularly mothers, to reflect on their lived experiences. Using memoir within a research study also highlights how narrative approaches can be part of the education of health-care professionals.

**Summary**

Families may suffer anxiety and depression, stress and burnout while caring for an adolescent with an eating disorder (De LA Rie et al., 2005; Kyriacou et al., 2008). They may also feel isolated and blamed by health-care professionals and receive little support, collaboration, or education about the disorder (Haigh & Treasure, 2003;
Furthermore, negative interactions between patients and health-care professionals may affect recovery (Honey & Halse, 2005).

Chapter 1 has provided the purpose and goal of the study, the research questions, and the research design. The significance of the study has also been addressed. Chapter 2 will provide a more detailed review of literature relevant to the study’s problem. In Chapter 3 I will discuss the research methodology and study design. Chapter 4 will present my personal memoir. In Chapter 5 I will present the findings based on the analysis of the data gathered from the online group discussions. Chapter six will answer the research questions. And finally, chapter seven will provide a summary of the research process and findings, address the gaps in knowledge, and offer implications for nursing practice, education, and research, and provide closing reflections.
CHAPTER TWO: LITERATURE REVIEW

The purpose of the literature review is to establish a picture of the current state of knowledge in several areas relevant to this inquiry including the struggles experienced by adolescents with eating disorders and the impact on families when an adolescent has an eating disorder. This review is aimed at revealing the gaps in knowledge relevant to the focus of this research, which is the importance of collaborative and supportive care by health-care professionals for families of adolescents suffering with an eating disorder.

I first examine the issues related to home life of families and adolescents suffering with eating disorders. Following this, interactions of family and adolescents with eating disorders with health-care professionals were explored. And finally, studies that considered health-care professional interactions with adolescents with eating disorders were reviewed.

A variety of textbooks and articles were used, and several electronic databases were explored including, CINAHL, MEDLINE, ProQuest Dissertations and Theses, Academic Search Complete, and Google Scholar. The following key words were used to search the literature: families, parents, children, adolescents, eating disorders, anorexia nervosa, nurses, health-care professionals, support, attitudes, and perceptions.

**Eating Disorders and Family Life**

Home life for families and persons suffering with eating disorders is associated with high levels of stress and burden (Treasure, Murphy, Szmukler, Todd, Gavan, & Joyce, 2001). This is compounded by the fact that eating disorders are poorly
understood and treatment inconsistent (Honey & Halse, 2005). Families struggle to find answers, make meaning of, and keep their family together during this turbulent time, which, according to Honey and Halse, can be difficult when realizing that their adolescent may not recover for many years, or not at all. Within the family unit, the person with an eating disorder also struggles with its effects, thus needing support from family, contact with friends, and experiences that improve self-esteem, in order to facilitate recovery (Halvorsen & Heyerdahl, 2007).

**Person with an Eating Disorder**

The aim of a qualitative study conducted by Patching and Lawler (2009) was to understand women’s experiences of developing an eating disorder and recovering. Interviews were carried out with 20 women who had recovered from an eating disorder. The study revealed that the development of the condition was attributed to a lack of control, a sense of non-connectedness to family and peers and extreme conflict with significant others. Recovery occurred when the women re-engaged with life, developed skills necessary for conflict resolution and rediscovered their sense of self. Patching and Lawler determined that having an understanding of eating disorders in the framework of the lived experience may assist in the development of a successful approach to treatment. Within family life the following sub-themes emerged from the study for persons with an eating disorder: pain and anxiety; and self-esteem.

**Pain and anxiety**

The purpose of a study by Button and Warren (2001) was to understand how persons with eating disorders view the disorder, how it affects their lives, and how they
experience treatment and help. Interviews were carried out with 89 patients with eating disorders. One person divulged:

I became very ill…I was in a terrible state…and now it just messes everything up because things I want to do I find difficult…it affects me socially because it's difficult to eat, physically because I have to push myself to do things. (p. 81)

The study uncovered that a wide variety of factors were thought to have played a part in causing the development of an eating disorder. Common themes within this study, however, centred on the issue of control and difficulties in relationships.

Pain and anxiety was also identified on the Caring Online (2014) website, which provides information on eating disorders and blogs of stories from those suffering. The following excerpt from the blog describes the intense pain one adolescent endured while suffering with an eating disorder:

Martel, K: We believe we are fat, useless, unworthy, unlovable, and weak. We honestly believe that losing weight will on some level make things better. We listen to the voices that constantly tell us we are not good enough, thin enough, strong enough, a little more and then we can stop. (Caring Online: To Bring Hope and Save Futures, 2014)

**Self-esteem**

In addition to pain and suffering, self-esteem was also considered a factor in recovery as described in a study conducted by Patching and Lawler (2009) noted above. One person stated that “her desire to lose weight stemmed predominantly from disparaging comments her father made about her weight and the association he made between her being physically unattractive and therefore ‘unlovable’” (p. 15). Another
person described her feelings: “my parents’ support has always been very conditional and they’ve never been the types to issue compliments or boost self-esteem and that definitely had something to do with developing an eating disorder” (p. 18). Halvorsen and Heyerdahl (2007) believe important factors in the recovery of persons with eating disorders are support from family, contact with friends, and experiences that improve self-esteem. In addition to this, families living with person with an eating disorder are significantly impacted and in turmoil and distress and yet, according to Haigh and Treasure (2003), family pain and needs are often overlooked by health-care professionals.

**Families of Persons with Eating Disorders**

Studies have shown that families are desperate to help the person suffering with an eating disorder (Haigh & Treasure, 2003); however, in order to do so, they need information regarding coping strategies, treatment options, prognosis, and future treatment plans. Hight, Thompson, and King (2005) point out that little attention has been devoted to the distinct experience of caring for a person with an eating disorder even though there are significant societal, personal, and familial impacts with respect to eating disorders. Within family life the following sub-themes emerged from the study for families of persons with eating disorders: emotions; strained relationships; financial struggles; and lack of knowledge and understanding.

**Emotions**

Family emotions such as anxiety, stress, exhaustion, depression, and feeling overwhelmed were evident in a literature review by Whitney, Murray, Gavan, Gill, Whitaker, and Treasure (2005). This qualitative analysis and computerized text
analysis were conducted on 40 narratives written by parents as part of a family intervention at a specialist in-patient unit. Findings revealed that families are often perplexed about the cause and contributing factors of the illness, with mothers and fathers equally placing blame on themselves, questioning aspects of their adolescent’s upbringing and what could have been done differently to prevent the illness. A qualitative study carried out by Cottee-Lane, Pistrang, and Bryant-Waugh (2004) examined the experience of families who had an adolescent diagnosed with an eating disorder. Semi-structured interviews were carried out with 11 family members. The results indicated that for the majority of families, having an adolescent with an eating disorder was overwhelming with no light at the end of the tunnel. One parent described life as a living nightmare:

I think you’ve got to bear in mind that the level of frustration a parent is feeling is extreme…because you might be living through this nightmare for a year, 18 months, longer you know who knows how long some parents go on for and it’s a level of torture that is unimaginable. (p. 173)

The aim of a Canadian study by Weaver (2012) was to represent the voices of parents and the meanings parents draw from their experiences in caring for a child with an eating disorder. A collaborative qualitative inquiry design was utilized and interviews were conducted with 29 parents. The findings revealed that caring for a child with an eating disorder was an overwhelming experience. One mother divulged that “caring for her child with an eating disorder was so traumatic she compared it to hell” (p. 412). The study also noted that parents were further traumatized when blamed for the child’s
illness. One mother was “blamed by the counselor for not eating properly when pregnant” (p. 412).

A cross sectional study led by Kyriacou, Treasure, and Schmidt (2008) explored factors associated with distress in 151 family members of persons with eating disorders. It was discovered that these families had high levels of distress, depression, and anxiety resulting in an impaired quality of life. Mothers, in particular, conveyed high levels of emotional distress. Maternal suffering was also identified in this excerpt from a story by Skovgaard (2011):

When I finally came to realize that I had no control over this illness, I lost my mind. I became depressed, anxious, and agoraphobic. I could only leave the house long enough to drive the girls to school and then come home again. And I did that only because Robyn was under doctor’s orders not to do any activity and was too weak to walk that distance. I missed six months of work and required weeks of day hospital care and therapy before I recovered enough to get parts of my life back. (pp. 15-16)

The literature also uncovered other emotions expressed by families including sadness, distress, fear, anger and hostility. Others expressed self-blaming emotions such as guilt and feelings of failure and inadequacy, which were evident in a literature review by Whitney et al. (2005). The purpose of their review was to gain an understanding of families’ illness models and family experiences. One mother in the study related, “So how does a mother feel? Failed, useless, bad, stupid, guilty, guilty, guilty” (p. 446). The study further uncovered that several families, mostly mothers, demonstrated an overwhelming emotional response. “I was very emotional and couldn’t
talk to anyone without crying and I could not sleep very well. And often cried myself to sleep as I could see what was happening to [her] and just felt helpless” (p. 447).

**Strained relationships**

In addition to these emotions, families struggle with lower energy levels and fatigue, loss of behavioural or emotional control, psychological well-being, and strain on family relationships; this was apparent in a study by De LA Rie, Van Furth, De Koning, Noordenbos, and Donker (2005). The focus of this study was to explore the daily life experiences of 40 families of eating disorder patients, psychological well-being, relationships, and their need for support. Families revealed that caring for the person with an eating disorder was too much to handle, and that they were unable to cope with this on their own, “I tend to feel anxious and worried. I can hardly enjoy anything. I do not want to leave her by herself. I feel imprisoned and powerless” (p. 348). A Canadian study carried out by Gilbert, Shaw, and Notar (2000) investigated the challenges that families face and the changes that occur, particularly in relationships, when an adolescent is diagnosed with an eating disorder, and how families cope with these changes. A detailed questionnaire using both quantitative and qualitative questions was completed by 52 mothers. One mother voiced her concern: “I was confused most of the time—when I thought I was helping, I wasn't. When I backed off she would accuse me of not caring” (p. 338). Another parent stated, “With no guidance from professionals working with our daughter we felt helpless...there were many conflicting views in the literature written on eating disorders” (p. 338). The negative impacts affected the day to day lives of families and the person with the eating disorder. Parents struggled to balance the relationship with the person with the eating disorder and other family
members. This was also evident in the study by De LA Rie et al. (2005) where one parent stated:

> It almost completely destroyed our relationship… I felt disappointed and sad by her behaviour and she felt, I think, that I didn't love her… I am trying to rebuild a relationship but I am always very careful around her… nothing is spontaneous. (p. 336)

Another parent in the study pointed out, “I think about it day and night. This affects my relationship with other family members. I do not give enough attention to my other daughters” (p. 348). This study also revealed that the illness contributed to conflict within the marriage. One mother remarked, “I feel it is putting strain on our marriage as [my husband] wants to get on with life” (p. 446). Along the same line, Sim, Homme, Lteif, Vande Voort, Schak, and Ellingson (2009) conducted a study to determine the nature of family distress in mothers of adolescents with eating disorders. Participants consisted of 93 mothers of adolescents with eating disorders. The results of this US study found that mothers experienced increased symptoms of depression and greater relationship conflict within the family unit.

**Financial struggles**

Along with emotions and relationship issues, the literature exposed another impact on families, namely, financial struggles as discussed by Hillege, Beale, and McMaster (2006). The aim of this US study was to consider the impact that an eating disorder had on the family. A qualitative approach using semi-structured interviews was used to explore the experiences of 19 mothers and three fathers living with an adolescent with an eating disorder. The results revealed that many parents spoke of
the eating disorder being financially draining. They spent large sums of money on health insurance, hospitalization, and therapists. Families made reference to the hidden costs of chronic illness and repeated hospitalizations such as transportation costs, food fads, additional family care costs, and time missed at work. One parent reported:

We're very grateful we have private hospital coverage and count the days I've got left...you wonder in the future, am I going to be able to afford for her to be in private hospital coverage when my hundred days per year runs out? (p. 1020)

The aim of a qualitative study by Highet et al. (2005) was to consider the distinct experience of caring for a person with an eating disorder. Six focus groups (three groups each consisting of two sessions), each comprising between six and eight family members of persons with eating disorders, were held. The results of the study identified many impacts to families. Several families indicated that they were required to devote all of their time and energy to care for the person with the eating disorder, sometimes to the extent that families ceased employment in order to care for their adolescent: “I had to give up work to care for my daughter” (p. 333). In Weaver’s (2012) study of parents’ perspectives of caring for a child with an eating disorder, she also found parents experienced financial burdens (p. 413).

**Lack of Knowledge and Understanding**

Not only is home life of families living with an adolescent with an eating disorder impacted by many emotions, strained relationships, and financial struggles, they are also burdened by a lack of knowledge and understanding as evident in a qualitative study by Hillege et al. (2006). Families in this Australian study often felt isolated and alone particularly when seeking support from friends and other family members. They
believed that the lack of knowledge and understanding led to inconsiderate words and confusion as discussed next.

**Inconsiderate words**

The qualitative study by Hillege et al. (2006) was carried out to explore the impact that an eating disorder had on the family, particularly the parents. Lack of understanding was apparent as parents struggled to hold the family together and cope with inconsiderate words from others. One parent disclosed: “I don’t think people realized there was anything wrong and if I did try and say anything to people who would be normally supportive, they didn’t know and they’d say things like ‘Oh well give her cake to eat.’…” (p. 1020). The aim of a qualitative analysis conducted by Whitney et al. (2005) was to gain an understanding of family experiences of caring for a person with an eating disorder. Letters from 40 mothers and fathers revealed that not only did they blame themselves for the illness families were deeply affected by the inconsiderate words and actions of others. A father in the study reported, “when she was very thin and we were all out together, I got very angry when people would stop and stare at her, nudge their companion to look as well” (p. 446). Hight et al. (2005) carried out a qualitative study using a combination of focus groups and individual in-depth interviews to explore the experience of 24 family members living with a person with an eating disorder. Families discussed how the lack of community awareness and understanding about eating disorders, coupled with stigma, further intensified these inconsiderate and judgemental comments not only for the person with the disorder, but also the parent. One parent in the study reported:
We were walking down the street together and there was a group of girls walking towards us, and just as we were passing, one of them said ‘Anorexic.’ And Amy just said, ‘Mum, it hurts’ . . . and that really hurt me too. (p. 334)

Lack of understanding was apparent as described by another parent in the study who talked about how the community’s inconsiderate comments and blame lead them to unwarranted feelings of shame and humiliation: “I would be embarrassed…she used to wear these tight clothes and her bones sticking out and she just looked pale…People think you’re doing it or ‘why don’t you stop it?’” (p. 334).

Confusion

Not only was lack of knowledge and understanding exacerbated by inconsiderate words from others, but families also experienced much confusion. Gilbert et al.’s. (2000) study identified that families were confused about why their adolescent developed an eating disorder, and how to help her. The study also brought to light that some of the confusion came from conflicting information from health-care professionals. One parent stated: “If professionals regarding eating disorders agree on one thing it’s that no one agrees on anything….each new therapist (as we are now on our fourth) has their own views on what parents should or should not do to help” (p. 338). Similarly, Weaver (2012) noted how parents were confused and disgruntled by the failure of professionals to recognize the eating disorder in initial visits or provide answers to managing their child’s care, “Nobody seemed able to tell you. They said don’t talk about eating, ignore. Well hello! Twenty-four hours a day, try to ignore it!” (p.412). Lack of knowledge and confusion was also reported by families in a qualitative analysis of narratives by Whitney et al. (2005). The findings, similar to other studies on mental
illness, revealed that family attempts to educate themselves about eating disorders left them confused and feeling guilty for not being able to help their adolescent: “Guilt is the most difficult to deal with because we still don’t know what has caused the anorexia” (p. 445). The purpose of a qualitative study carried out by Highet et al. (2005) was to look at the progression of eating disorders in order to understand its impact on family members of adolescents with eating disorders throughout the stages of the illness. This study identified that family stress was due to confusion from lack of understanding about the illness: “everybody in the family was really shocked…but nobody ever…provided me with anything, any understanding” (p. 334). The outcome of a qualitative study by Cottée-Lane et al. (2004) indicated that parents sought information on how to manage the adolescent from a variety of sources such as other family members, friends and professionals. However, advice was often conflicting and families remained confused as voiced by one parent: “If you go and ask a dozen people, what should I do? You’ll have a dozen different answers, and I just wanted to have it in my head, right from the outset” (p. 174).

**Family Interactions with Health-Care Professionals**

The literature identified issues related to interactions between families and health-care professionals and its impact on recovery of an adolescent with an eating disorder. The prominent themes included: a lack of information from health-care professionals; being excluded in treatment plans; and lack of trust and support by health-care professionals.
Lack of Information from Health-Care Professionals

The aim of a focus group study carried out by Haigh and Treasure (2003) was to determine the needs of 28 family members of persons with eating disorders. The study revealed that families wanted “information about what treatment was available, information about the prognosis and plans for future treatment. They also expressed a need for help with coping strategies” (p. 130). Families also voiced the need for “family doctors to be more informative about the organizations that are available for help and/or advice and the treatment options available to someone with an eating disorder” (p. 133). Families emphasized that if they were provided with this information, then not only would their distress be decreased, but they would also be more effective in supporting the person they are caring for. The goal of a qualitative study carried out by Honey and Halse (2005) was to examine coping strategies families used to deal with the demands of having an adolescent diagnosed with an eating disorder. In-depth interviews were carried out with 22 parents of adolescents with eating disorders. The study results determined that information seeking was a high priority for families. They tried to find out all they could about eating disorders by questioning health-care professionals, reading books, researching on the Internet, and talking to other women with eating disorders and their relatives. As well, families sought specific advice from health-care professionals, support groups, and informal networks with regard to interpreting their adolescents’ behaviours and what they should do for their adolescent. One parent stated:
You can ring up and…say, well, you know, you know, should I be doing this?...

They’re often very constructive, particularly with things that I might find very
difficult to get [my daughter] to do. (p. 617)

Similarly, the aim of a qualitative study conducted by Cottee-Lane et al. (2004) was to
explore the experiences of parents living with an adolescent with an eating disorder. Of
particular interest was how families viewed the impact of their adolescent’s eating
disorder on themselves and the family as a whole, and how they made sense of and
coped with the illness. Many families stated that despite their best efforts to understand
why their adolescent had developed an eating disorder they remained puzzled. Results
emphasized the quest for understanding was important to families and was often driven
by their desire to try to help their adolescent on the road to recovery. One parent
stated, “I think it certainly would be helpful…knowing what’s going to happen, knowing
what to expect” (p. 176).

**Being Excluded in Treatment Plans**

The literature was clear that families wanted and needed more information from
health-care professionals about eating disorders in order to understand and provide the
care their adolescent needed. Furthermore, many families feel shut out, excluded, and
even blamed by health-care professionals as identified in a study conducted by
McMaster, Beale, Hillege, and Nagy (2004). The participants identified that health-care
professionals need to acknowledge that families are integral to the recovery process
rather than shutting them out. This was expressed by a mother:
The message to parents is I’m seeing your child, I’m taking over from you...you stay home...It’s insulting to a person like me...I’ll do whatever it takes. But don’t shut me out and treat me like a moron...It makes me angry. (p. 70)

A comparable qualitative study directed by Tierney (2005) investigated the experiences of families with an adolescent who had received treatment for an eating disorder. Semi-structured interviews were used to collect data from six sets of parents living in the UK. The outcome of the study pointed out how health-care professionals often excluded families from or informing them about their adolescent’s care. One parent expressed:

We were at the stage where we’d been [patient]’s mum and dad for 16 years, and we were used to working problems through with her, and then suddenly these barriers came down and we felt that things were happening to her and being discussed with her and that we were being blocked out of it, yet we were the ones she had to come back to when they had had their little go with her. (p. 374)

These negative interactions left families feeling isolated and unclear about their adolescent’s prognosis. Likewise, the aim of a qualitative study carried out by Highet et al. (2005) was to explore the distinct experience of caring for a person with an eating disorder. Outcomes revealed that families often “felt they were often uninformed about the illness and treatment options or were not included in discussions about progress and care management” (pp. 338-339).

Lack of Trust and Support by Health-Care Professionals

In addition to lack of information and being excluded in treatment plans, families of adolescents with eating disorder felt a lack of trust and support by health-care professionals as identified in a qualitative study carried out by Honey and Halse (2005).
The findings spoke to not only the lack of support for families but also the lack of trust families had towards health-care professionals. Families described trying to influence the adolescents’ experiences with treatment by negotiating with health-care professionals about treatment strategies and options, advocating as to what the adolescents wanted. Many families described having to “bite their tongue and to avoid criticising or complaining to ensuring good treatment for their daughter” (p. 360). Another parent described her concern:

   You know, we’d sort of put ourselves in the hands of the doctors then. Obviously we hadn’t been able to fix the problem, so we had to hand her over. And so part of that was putting up with whatever treatment we got. We had to. We had to rely on them totally. (p. 360)

   Lack of trust support was also apparent in Weaver’s (2012) study of parents’ experiences of caring for a child with an eating disorder (p.415). Interactions between families and health-care professionals were also the subject of a study by De LA Rie et al. (2005). The families highlighted that they wanted and needed support on how to handle the problems encountered at home without losing sight of their own needs. One parent said, “I notice I need practical advice to handle certain situations” (p. 350). Another parent recognized that “you need to speak to someone, just to get it off your chest” (p. 350).

   Parents are often the main caregivers of adolescents with eating disorders. The findings in the literature report negative impacts such as a lack of information from health-care professionals, being excluded in treatment plans, and experiencing a lack of lack of trust and support by health-care professionals.
Persons with Eating Disorders and Interactions with Health-Care Professionals

The literature uncovered negative impacts regarding interactions between families and health-care professionals. Along with the families' experience it is important to consider how persons with eating disorders interactions with health-care professionals affected their perceived degree of recovery. The purpose of a study by Button and Warren (2001) was to understand how persons with eating disorders view the disorder, how it affects their lives, and how they experience treatment and help. Interviews were carried out with 89 patients with eating disorders. The patients described a loss of control in one or more areas of their lives, often centering on their self-image and problems in relationships with others. The outcome of the study found that patients placed importance on individual psychotherapy and counselling and on the quality of relationship with health-care professionals. A qualitative study carried out by Patching and Lawler (2009) explored women’s experiences of developing an eating disorder and recovering. The study identified a need for a clearer understanding by health-care professionals of the development of the disorder and risk factors before treatment regimes and therapeutic relationships can be effective with these patients.

Although the literature brought to light themes similar to those of families' interactions with health-care professionals, other themes were also identified which will now be discussed. These themes included: being cared for; communication and collaboration; and therapeutic relationships.

Being Cared For

Colton and Pistang (2004) explored how persons with eating disorders experienced inpatient treatment. The study results uncovered important views from
persons with eating disorders such as feeling cared for by staff on the unit. The availability and willingness of health-care professionals to listen to these persons as individuals was felt to be very important to recovery. This point was made by one person who said, “I just wish I could speak to someone but I just can’t ‘cause they always, they only focus on the people who scream” (p. 312). Similarly, a qualitative study by Petterson and Rosenvinge (2002) looked for factors that persons with eating disorders identified as contributing to their recovery. The study involved 48 women with eating disorders who took part in interviews and answered questionnaires. Positive attitudes by health-care professionals were the strongest factor associated with recovery including empathy, being cared for, support, respect, and understanding. A common response in the study was “I got the feeling that the therapist really cared about me, I trusted her and I didn’t need to cover up” (p. 66). In other words, persons with eating disorders wanted to know the health-care professional had a caring attitude, were engaged, listened to them, and were available. Gulliksen, Espeset, Nordbo, Skarderud, Geller, and Holte (2012) explored health-care professional characteristics preferred by persons with eating disorders. Thirty-eight women with an eating disorder were interviewed in depth using a phenomenological study design. It was revealed that when health-care professionals were caring, kind, and understanding, persons with eating disorders felt secure, trusted, and cared for. One person stated:

I feel that he is understanding and tries to explain things. His whole body language and the way he talks (sobbing) makes me feel…(whispers)…that he cares about me and that I’m as valuable as anybody else. (p. 935)
Button and Warren (2001) explored how persons with eating disorders viewed the disorder, how it affected their lives, and how they experienced treatment and help. These persons were asked about helpful and unhelpful treatment they received. One person responded:

I felt they didn't really care about the individual. I felt they were all of a mass of what they were trying to do for people with eating disorders in general, that you weren't separate people. (p. 85)

**Communication and Collaboration**

Along with wanting to be cared for, persons with eating disorders also deemed communication and collaboration as an important factor in recovery, according to Offord, Turner, and Cooper (2006). This qualitative study explored persons with eating disorders' views regarding the inpatient treatment they received in adolescence. Semi-structured interviews were conducted with seven young adults treated in general adolescent psychiatric units. Results showed that many of these persons felt controlled and powerless versus a sense of collaboration with health-care professionals about their own treatment and recovery; this powerlessness was not conducive to recovery:

They have this set programme and like, for instance, I have never had a problem with being sick, or anything like that, and the idea that I couldn’t go to the loo in case I’d be sick was just like bizarre because it didn’t apply to me. And they all knew that it didn’t apply to me, but they said “well we’ve got to do this cause it’s the rule. (p. 381)

Colton and Pistang (2004) also explored how persons with eating disorders experience inpatient treatment. This qualitative study used semi-structured interviews
to collect data from 19 adolescents in two inpatient eating disorder units. Some persons felt they were not encouraged to collaborate in their treatment: “It’s a place for hell…you’re stuck in here and you can’t get out, you can’t do anything” (p. 312). A study by Button and Warren (2001) explored how helpful treatment or help had been for persons with eating disorders. One person stated, “I was helped in a different way which was much better. People were prepared to talk and understand why I was doing it rather than punishing me for doing it” (p. 84). Another person stated:

…just having someone to talk to is important, telling them how you feel and them suggesting other ways of approaching it, other ways of thinking, somebody outside your family and friends, someone independent. (p. 84)

A qualitative study carried out by Gulliksen et al. (2012) explored health-care professional characteristics preferred by persons with eating disorders. These persons were asked to describe positive and negative encounters with health-care professionals that they experienced during treatment. Collaboration was important to one person:

It’s important that they get to know you so that the health-care professional and the patient are kind of equal in the relationship. I have felt a great difference when it comes to that. (p. 935).

**Therapeutic Relationships**

Along with being cared for, having good communication and engaging in collaboration, therapeutic relationships were identified as important to recovery for persons with eating disorders. According to Priebe and McCabe (2008):

Therapeutic relationships and communication are related terms. Communication signifies the behavioural exchange between patient and health-care professional
that is observable and may be described in objective terms by an independent observer, and the relationship is a psychological construct held by the participating individuals on each other and their interaction. The way patient and health-care professional relate to each other influences how they communicate, and their communication influences how they think and feel about each other, i.e. their relationship. (p. 522)

A qualitative study carried out by Colton and Pistang (2004) explored how persons with eating disorders experience inpatient treatment. When these persons found that health-care professionals were interested in them, collaborative, and provided positive feedback when they improved, they more often wanted to comply. However, when health-care professionals were found to be punishing and dictatorial, this led to persons with eating disorders feeling rebellious. These have important considerations for health-care professionals. The aim of a Norwegian study by Gulliksen et al. (2012) was to identify the characteristics that persons with eating disorders prefer in health-care professionals. These persons described positive and negative encounters with health-care professionals that they experienced during treatment. Study results identified positive encounters as ones that made persons with eating disorders feel understood, cared for, safe, valuable, and in a better mood, and thus engaged in a therapeutic relationship with the health-care professional. One person stated: “she was so good to talk to and...she was kind of cheering you up and...was a bit humorous. She was kind of...a bit relaxed” (p. 936). Persons with eating disorders said that negative encounters made them feel lonely, less valuable, stupid, and disrespected. One person noted: “the worst thing is when they are sitting
there, telling me how I feel. Then I feel weird. I know best for myself how I feel inside” (p. 936). Another person stated, “all those times I never felt any compassion or heartfelt concern. I can still feel those looks directed at me—looks that tell you that you have yourself to blame for this” (p. 936). A combined quantitative and qualitative study carried out by De LA Rie, Noordenbos, Donke, and Van Furth (2008) investigated the quality of treatment of eating disorders from both the health-care professionals’ and persons’ with eating disorders perspectives. Questionnaires were administered to 73 health-care professionals working with patients with eating disorders, and to 156 persons currently being treated for an eating disorder, and 148 former persons with eating disorders. Highlighted in the study was that both health-care professionals and persons with eating disorders believe that a therapeutic relationship and communication skills are important aspects of the quality of treatment. Several persons stressed the “importance of acceptance and a good therapeutic alliance, because they found it particularly challenging to engage in a relationship with a therapist” (p. 314).

And finally, a study conducted by Button and Warren (2001) asked if persons with eating disorders had any comments about treatment or help. One person offered, “you need to see someone professional on a one-to-one. You’ve got to have trust and build a relationship and get on with them” (p. 87).

Persons receiving treatment for an eating disorder want to be cared for, listened to, have good communication health-care professionals, as well as engage in therapeutic relationships. The literature identified that persons with eating disorders found these attitudes and behaviours paramount to their healing process and
furthermore that these approaches were for the most part absent in their experiences with health-care professionals.

**Health-Care Professional Interactions with Patients with Eating Disorders**

Health-care professionals play a key role in facilitating the successful treatment of patients with eating disorders as they are with them 24 hours a day in hospitals providing both physical and emotional care. A naturalistic inquiry study was conducted by Ramjan (2004) with 10 nurses from the acute wards of an Australian children’s hospital. The data were collected using semi-structured interviews. Health-care professionals in the study identified their struggle to understand the complexities of eating disorders, and how they therefore experienced difficulties implementing the prescribed treatment program. Despite a lack of understanding of the disorder, health-care professionals endeavour to provide patients with eating disorders respect, empathy, acceptance, honesty, and therapeutic relationships (Bakker et al., 2011; Colton & Pistrang, 2004; Tierney, 2008). The themes gleaned from the literature in regards to health-care professional interactions with patients were: lack of knowledge and understanding; stress and burnout; trust and power struggles; and therapeutic relationships.

**Lack of Knowledge and Understanding**

Health-care professionals are lacking knowledge and understanding of eating disorders and treatment, according to Vandereycken (2006). This systematic literature review analyzed the concept of denial of illness in eating disorders, especially with regard to its clinical and diagnostic significance. The review identified that health-care professionals’ understanding about eating disorders influenced the types of experiences
they had when working with eating disorder patients. This was also evident in a literature review led by Thompson-Brenner, Satir, Franko, and Herzog (2012) who sought to review all published empirical studies of health-care professional's reactions to patients with eating disorders in order to characterize negative reactions to these patients and identify patient or clinical factors associated with negative reactions. The review found that health-care professionals across disciplines reacted strongly to patients with eating disorders due to a lack of knowledge. This triggered reactions such as frustration, hopelessness, lack of competence, and worry by health-care professionals. King and Turner (2000) chose a qualitative design to explore the experiences of health-care professionals caring for adolescents with eating disorders within pediatric wards of general hospitals in Australia. In-depth interviews were carried out with five registered nurses. The results revealed a lack of knowledge by health-care professionals caring for patients with eating disorders. The health-care professionals in the study did not have formal educational qualifications in mental health or psychiatric nursing which suggested the need for on-going education to support health-care professionals caring for patients with eating disorders. An older (1992) study by Fleming and Szmukler considered attitudes to eating disorder patients among the two major professional groups, medicine and nursing. A questionnaire examining attitudes to patients with eating disorders was completed by 352 medical and nursing staff in a general hospital in New Zealand. The study revealed that patients with eating disorders were not very well liked by the health-care professionals, and the correlation between

3 Some older studies are included in this literature review as they are done by pioneers in this area of study.
lack of knowledge about the disorder and unhelpful attitudes from health-care professionals was significant. It is unfortunate that these findings have not changed significantly in the last few decades as reported in the studies in this literature review.

**Frustration and Burnout**

Along with a lack of knowledge and understanding, the literature made it clear that health-care professionals struggled with feelings of frustration and burnout while caring for patients with eating disorders as reported in a study by Ramjan (2004) earlier. Findings identified that health-care professionals found working with patients experiencing eating disorders personally challenging with high rates of stress, burnout and frustration. Many health-care professionals believed that these patients had caused their own harm and needed to fix it themselves:

Frustrating…there’s nothing pinpointing why they’re that way. It’s all in their heads. There’s no set guidelines as to ok this is what you’ve got to do to fix it…they have to fix it themselves. Basically…when there’s really unwell kids on the ward…you think how can you be doing this. (p. 498)

The aim of a study by Snell, Crowe, and Jordan (2009) set out to investigate and theorize the experiences of health-care professionals in developing a therapeutic relationship with patients being treated for eating disorders. This qualitative study explored nurses’ descriptions of practice in an inpatient eating disorder unit. Seven health-care professionals agreed to be interviewed. Health-care professionals found developing therapeutic relationships was difficult as they struggled with feelings of frustration while caring for patients with eating disorders. One health-care professional stated:
You need a lot of self-control, to be able to go back to the patient again and again… also self-control to remember to not get frustrated and when you go here we go again for the 20th time and you just have to go ‘ok this is what the person needs to do’ for the 20th time. (p. 355)

A qualitative study by King and Turner (2000) considered the experiences of health-care professionals caring for adolescents with eating disorders within pediatric wards of general hospitals in Australia. In-depth interviews were carried out with five registered nurses. The findings revealed that health-care professionals found caring for a patient with an eating disorder particularly challenging. Daily frustration overwhelmed health-care professionals as “they reached a point where they had had enough. The warring, frustration, being hurt and lack of success eroded their resilience so much that they could not cope with the situation anymore and turned off” (p. 143). This was affirmed by a health-care professional who said, “… we could not get through to them. They never trusted us enough to confide in us…all of us were really, really tired of…fighting with these girls…” (p. 143). Study findings identified the need for extensive registered nurse preparation, on-going support, and development of education programmes to enable health-care professionals to care for patients with eating disorders with greater understanding and less frustration.

**Trust and Power Struggles**

A qualitative study carried out by Snell et al. (2009) explored nurses’ descriptions of practice in an inpatient eating disorder unit. The outcome revealed that health-care professionals pride themselves on building therapeutic relationships—based on honesty, a nonjudgmental attitude, and respect—with patients with eating disorders in
order to facilitate the healing process. Research, however, has shown that health-care professionals are struggling with a lack of knowledge and understanding of eating disorders, thereby wrestling with feelings of frustration and burnout. In addition to this, health-care professionals find themselves battling issues of trust and engaging in power struggles with patients with eating disorders. Ramjan’s (2004) naturalistic study as noted earlier explored the difficulties and obstacles hindering the formation of therapeutic relationships in this context. Power struggles between health-care professionals and patients with eating disorders were revealed in the study with health-care professionals enforcing compliance to eating disorder programmes and patients refusing to relinquish control and cooperate. According to one health-care professional, these patients often resorted to manipulation by “playing one nurse off against another” or ‘lying’ or ‘twisting words around’ to gain ‘control’” (p. 499). Health-care professionals found this difficult: “it’s all a question of…an emotional and psychological battle with them and that constant battle can be…quite…distressing for some staff” (p. 498).

Similarly, the aim of an Australian study by Ryan, Malson, Clarke, Anderson, and Kohn (2006) was to illuminate some of the complexities and challenges involved in treating eating disordered patients. A qualitative study was used to interview 15 health-care professionals about nursing children and adolescents diagnosed with eating disorders. Highlighted was the power struggles between health-care professionals and patients with eating disorders. One health-care professional stated, “patients are so challenging. They’re very cunning, and manipulative…you just have to let them know who’s boss but sometimes if there are so many of them it’s a battle” (p. 130). Study outcomes confirmed that trust and commitment, empathy, support, consistency, and a non-
judgemental attitude are essential in developing therapeutic relationships with patients diagnosed with eating disorders.

**Therapeutic Relationships**

The literature has identified that health-care professionals are struggling with lack of knowledge and understanding when caring for patients with eating disorders. In addition, Ramjan (2004) discussed health-care professional’s feeling of frustration, burn out, trust issues, and power struggles have been shown to interfere with developing therapeutic relationships. According to Wright (2010), the establishment of a positive therapeutic relationship has been widely acknowledged internationally as an intrinsic part of therapy and caring services, even healing and restorative in its own right. Research by Snell et al. (2009) found that the very nature of eating disorders is associated with denial and resistance to treatment, as well as the health-care professionals’ attempts to establish therapeutic relationships. Shattell, Starr, and Thomas (2007) stress that patients with eating disorders want health-care professionals to ‘really know them’ and share the power, but this is difficult amid a climate of criticism and the subsequent frustration felt by health-care professionals, which evokes a sense of failure. According to Ramjan (2004), there is plenty of research showing the importance of developing therapeutic relationships with patients with eating disorders, and yet, there is still insufficient research to provide an in-depth understanding of these difficulties and why they develop or of how health-care professionals believe therapeutic relationships might be improved. A qualitative study carried out by Snell et al. (2009) explored nurses’ descriptions of practice in an inpatient eating disorder unit. The study outcome revealed that health-care professionals desire to build therapeutic relationships
was based on honesty, nonjudgmental attitudes, and respect in order to facilitate the healing process. The study investigated the experiences of health-care professionals in developing a therapeutic relationship with patients admitted to an eating disorder inpatient service. The study’s outcome highlighted the ways in which health-care professionals managed their emotions and responded therapeutically to the patient required self-awareness. One health-care professional described her self-awareness:

I think it’s again, really important to not take things that are happening with that person personally and always come back in fresh, like don’t hold anything against that person. (p. 355)

Summary

Negative interactions between persons with an eating disorder and health-care professionals affect recovery while therapeutic relationships, based on empathy and awareness, are conducive to recovery (Colton & Pistang, 2004; De LA Rie et al., 2008; Gulliksen et al., 2012; Priebe & McCabe, 2008). Patients voiced the desire to be involved in their own care, which meant collaborating in decisions (Button & Warren, 2001; Colton & Pistang, 2004; Gulliksen et al., 2012; Offord et al., 2006). Furthermore, it was evident from the reviewed studies that families suffer anxiety and depression, stress, burnout, strained family relationships and financial struggles while caring for an adolescent with an eating disorder (Cottee-Lane et al., 2004; De LA Rie et al., 2005; Gilbert et al., 2000; Hilleg et al., 2006; Hight et al., 2005; Honey & Halse, 2005; Kyracou et al., 2008; Sim et al., 2009). It was also obvious that families lack knowledge and understanding of the disorder, feel excluded in treatment plans and unsupported by health-care professionals (Cottee-Lane et al., 2004; De LA Rie et al., 2005; Haigh &
Additionally, the literature highlighted that health-care professionals also lack knowledge and understanding necessary for providing care and treatment to patients with eating disorders (Bakker et al., 2011; Colton & Pistrang, 2004; Fleming & Szmukier, 1992; King & Turner, 2000; Patching & Lawler, 2009; Tierney, 2008; Vandereycken, 2006). Feelings of frustration, burnout, trust issues, and engagement in power struggles with patients with eating disorders also negatively impact care (King & Turner, 2000; Ramjan, 2004; Ryan et al., 2006; Snell et al., 2009). Therapeutic relationships were also identified as an intrinsic part of therapy (Ramjan, 2004; Shattell et al., 2007; Snell et al., 2009; Wright, 2010). It is apparent that there are gaps in knowledge of health-care professionals, both in terms of understanding the importance of supporting patients and families of patients with eating disorders, and the benefits of a collaborative care approach. I, therefore, will endeavour to fill in the gaps and facilitate a dialogue towards new understanding of the importance of collaborative and supportive care by health-care professionals for patients and families of patients with an eating disorder.
CHAPTER THREE: METHODOLOGY AND RESEARCH DESIGN

The goals of this research study were a) to provide a first person account of the negative impacts on parents when health-care professionals blame and judge parents; and b) to explore the responses of health-care professionals to the memoir. I hoped this inquiry would provide further educational understanding and evidence regarding the importance of collaborative and supportive care by health-care professionals for families of adolescents suffering with an eating disorder. Considering one of the key objectives of my study was to deepen my own understanding about being the parent of an adolescent with an eating disorder and the impact of my encounters with health-care professionals, a qualitative research method seemed the most appropriate. To address the above goals and my research questions, this research design encompassed a two stage method. Part one comprised a memoir, and part two involved an online focus group.

**Stage One: Memoir**

The power of parental stories to break the silence about parents’ challenges in caring for a child with an eating disorder was a key contribution of Weaver’s study (2012) (see discussion in the literature review); the sharing of parents’ stories in that study also enabled transformational activism (p. 416). I hoped my story would lead to similar results and so I returned to the memoir I had written earlier.

After my daughter recovered from her eating disorder in 2006, I was left feeling traumatized and fearful of a relapse. I do not routinely journal, nevertheless, as an outlet for my feelings, I decided to write about my experience hoping to make sense of what happened. It was one of the hardest things I have ever done. While writing, I
would cry so hard that I had to stop and walk away. Remembering brought the fear, guilt, and anguish of my daughter’s suffering back to the present, and I couldn’t bear it. I persevered over the weeks, and when my story was finished, I had an amazing sense of peace and closure. Writing helped me look at the experience from a different perspective. The fear, guilt, and anger somehow lost its power in the writing. I was able to look at the situation more objectively and realize I wasn’t the reason my daughter developed an eating disorder. I didn’t cause it. The sense of peace was overwhelming.

I mentioned my story to a friend and she asked to read it. I sent it to her with some trepidation as it was so personal and raw. I wasn’t sure if I could bare my feelings and private thoughts to others. The next day she phoned crying and told me it was such a powerful story that I should share it with other mothers who have a daughter with an eating disorder as it might provide support and encouragement to them. Inspired by her uplifting words, I read my story to parents at the eating disorder recovery centre where my daughter had attended. When I finished reading I looked up and was stunned at the response. Many parents were weeping and some walked over and hugged me. I remember one parent saying “you could substitute my name in your story…it is exactly the same.” Another parent said, “you should publish this…parents need to read this.” This birthed the idea of offering a collection of true inspirational stories written by mothers to provide the much-needed encouragement, hope, and support to other mothers beginning their painful family journey. Several submissions, including mine, are included in my book titled A Melody of Hope: Surviving your Daughter’s Eating Disorder published in 2011.
My nursing colleagues on the pediatric unit at the hospital where I am employed read the book and shared how they cried after reading it and that it changed their view of the patients and their families. My colleagues also affirmed that they were determined to be more understanding and caring. They realized that everyone has a story and needs compassion. I became fascinated by the power of memoir. How can stories evoke such passion and resolve? This led to the decision to explore more fully how memoir could change nursing practice as my dissertation topic.

Although I was thrilled that my story had such an impact on parents and my colleagues, I recognized that my story focused mainly on my experience as a mother, but there was little mention of my interactions with health-care professionals or my role as a pediatric nurse caring for adolescents with eating disorders. I wondered if my story could have an even greater impact if these areas were explored more fully. Could my memoir contribute to changing attitudes, knowledge, and practice of health-care professionals?

With this question in mind, my personal memoir, although part of a collection of memoirs previously published in my 2011 book, was significantly revised. I put into words my journey through my daughter’s experience of her eating disorder from the perspective of being a mother, my interactions with health-care professionals and a health-care professional caring for adolescents with eating disorders. It was hoped that my unique perspective would shed light on how experiences with health-care professionals affect families and ultimately impact the recovery of adolescents with eating disorders. I believe this will add to the body of literature exploring the
experiences of parents with an adolescent with an eating disorder in relation to interactions with health-care professionals.

I found the process of writing and then revising my memoir echoes what Armstrong (2006) notes about how memoir is not only telling an autobiographical story; it is also a reflective, thoughtful form that requires the writer to reach beneath and beyond her own story in order to discover, analyze, understand, and communicate meaning beyond and beneath the events in the story, a meaning that is inter-subjective and reflexive. Like Armstrong, I found that writing a memoir is a process of discovery, a journey towards new understanding. Leggo (2008) provides further insight into memoir:

> Everybody lives stories, all the time, and everybody attends to the stories of others. And not only do we tell stories to ourselves and one another, but there are many stories that we have, at best, only limited access to, including the stories of dreams, fantasy, imagination, and memory. We hear and witness stories in our homes, in schools, in public spaces, in places of worship; we attend to stories on television and in movies; we understand the past in stories, and we seek to know the future in stories. (p. 3)

Di Summa-Knoop (2013) believes that the intention of memoir is to research the identity of the person as the narrator of his or her own life. The author maintains that “autobiographical narratives cannot be taken at face value; they often include omissions, alterations, and the possibility of a proliferation during the course of life” (p. 136). Conway (1998) as I cited earlier, best describes the purpose and goal of writing my memoir:
Every autobiographer wants to persuade others to learn from her or his life, take up some important cause, follow a new spiritual path, be aware of particular hazards, and develop a new moral sense. (p. 16)

**Stage Two: Focus Group**

As noted earlier, my study design included two stages: the first was writing my memoir, and the second was sharing the memoir with health-care professionals and gathering their responses to the story. In order to undertake the second part, an online focus group was created consisting of health-care professionals who read my memoir and then responded to predetermined open-ended online questions.

Focus groups, according to Jayasekara (2012), are an increasingly popular method of data collection in nursing research. It is well established that the “focus group method is a useful and effective mechanism in which the researcher is interested in processes whereby a group jointly constructs meaning about a topic” (p. 411). Jayasekara further believes that focus group discussions are not only used to gain new knowledge or evaluate services and programs but also to seek opinions, values, and beliefs in a collective context. Doody, Slevin, and Taggart (2013) state that the purpose of focus groups is to understand rather than infer, to determine the range rather than generalise, and to gain insight into how people in the groups perceive situations rather than make statements about the population. Focus groups are carried out when specific information is needed from people with certain characteristics and similar knowledge about a particular topic. This is because individuals in a group may be more willing to express views when they perceive that others are similar to them (Krueger; Litosseliti, as cited in Doody et al., 2013). Cochran (2013) asserts that although focus
groups are an economical (time and resources) method of understanding a social issue, they are often chosen as the method of inquiry because the collective information gained often mirrors the social context where the phenomena of interest is experienced. Cochran also points out that when focus groups are conducted with populations who have less power and status in society and are mistrustful of researchers, comfort, and openness increase because participants are surrounded by a group of peers who share similar life circumstances. Kinnear and Tarrant (as cited in Letendre & Williams, 2014) believe there is a “snowballing” effect in focus groups, in which the process interaction stimulates participants to share opinions, ideas, and feelings. As individual opinions are shared, other members reflect and compare opinions and respond in ways that agree with, add to or challenge the viewpoint.

While there are many advantages to using focus groups in research, there are also some limitations. Letendre and Williams (2014) discuss some concerns associated with focus groups:

There are methodological challenges that researchers must address for the groups to effectively accomplish their purpose. Organizing a setting where the focus group can meet in comfort and safety, and recruiting multiple participants who may be hesitant to be part of research projects must be addressed. (p. 115)

Some of these concerns may be addressed by exploring the notion of online focus groups. According to Oringderff (2004), online focus groups are an emerging qualitative method that enables researchers to capture primary data. A study carried out by Kenny (2005) explored the notion of online focus groups and found that participants felt more comfortable suggesting ideas, worried less about what others
thought of them, and felt more comfortable discussing sensitive issues when using the online approach. Graffigna and Bosio (2006) also conducted a study comparing face to face and online focus groups noting that although face to face focus groups permitted a large amount of verbal and nonverbal data, some problems came to light. The management of turn-taking in the discussions was problematic due to the occurrence of some participants monopolizing the talk. Also notable was that “participants seemed to avoid expressing their points of view, frequently making use of impersonal constructions, such as ‘people think’ and ‘they say’” (p. 64). Graffigna and Bisio noted that although interaction among the online focus group was not as frequent as the face to face focus group and focus group participants were mainly carrying out a sort of reflective monologue, these authors found that participants believed the online forum to be a place to “share their thoughts with people whom they were not afraid of being judged by, which allowed greater openness and freedom of expression, compared to a face to face group” (p. 65).

O’ringderff (2004) states there are two main types of online focus groups: synchronous and asynchronous. Synchronous focus groups are similar to traditional face-to-face focus groups as they feature real time interaction between the moderator and participants; however, it can be difficult to get all participants together online at the same time. As well, participants with slower typing skills may struggle to keep up to real time discussions. Furthermore, synchronous focus groups do not allow much time for participant reflection prior to responding. In asynchronous groups, participants log in and answer discussion topics on their own time. Asynchronous groups overcome time differences, variable typing skills, and provide more time for participants to focus and
reflect on responses. As a result, online focus groups can produce in-depth, rich responses.

**Focus Group Selection Criteria and Recruitment**

As noted in my literature review, the majority of health-care professionals (regardless of location and practice context) struggle with a lack of knowledge and understanding necessary for providing care and treatment to persons with eating disorders (Bakker et al., 2011; Colton & Pistrang, 2004; Fleming & Szmukier, 1992; King & Turner, 2000; Patching & Lawler, 2009; Tierney, 2008; Vandereycken, 2006). The literature also revealed that health-care professionals experience feelings of frustration, burnout, have trust issues, struggle to develop therapeutic relationships, and engage in power struggles with patients (King & Turner, 2000; Ramjan, 2004; Ryan et al., 2006; Shattell et al., 2007; Snell et al., 2009; Wright, 2010).

The literature review also indicated that my pediatric unit was typical with respect to the demographics of the nurses in the literature, and so I selected my colleagues as my participants. My sampling approach was thus both a matter of convenience, they were close at hand and I had access to them and it was also purposeful. I knew they had experience in caring for families and adolescents with eating disorders. We have had several discussions over the years about our collective lack of understanding of this disorder and ability to effectively support children and families and they had expressed an eagerness to learn more.

Carrying out research within the arena of my own nursing practice environment adds rigor to this study. I am not a distanced researcher, unaware or uneducated about the actual practice environment of my study participants and so including my colleagues
in the study, enhanced my capacity to see the impact of the memoir and also allowed participants lots of opportunity to engage with me, raise questions about the study, and share their thoughts. I believe a study such as this can be a catalyst for change or improving practice.

I was also aware that my colleagues may have felt obligated to participate due to our long term working relationship. There was a possibility that they may not have felt comfortable responding honestly to questions related to my personal memoir; they may have been afraid of repercussions in discussing concerns they had with current care and treatment of adolescents on the pediatric unit where they were employed.

The selection criteria I used to invite my colleagues to participate in the focus group were:

- At least one year post nursing registration experience
- Working on the pediatric unit with children and adolescents
- Caring for families and patients with eating disorders.

My colleagues work on a rotating shift schedule and hence it was difficult to schedule interviews, traditional face to face group discussions, or a synchronous online focus group. I therefore used an asynchronous online focus group method. It was my hope that this forum would facilitate a rich discussion and facilitate a dialogue towards new understanding of the importance of collaborative and supportive care of families of adolescents suffering with an eating disorder.

To recruit participants, the Patient Care Coordinator of the pediatric unit at a Western Canadian hospital where I work sent an email recruiting participants working on this unit to be part of my research by reading my memoir and participating in an
online focus group. Seven health-care professionals responded to this invitation. They ranged in age from 24 to 57 with a range of pediatric nursing experiences from 2.5 years to 35 years. Their educational credentials reflect the changes in nursing education requirements with younger participants acquiring nursing degrees and older participants acquiring nursing diplomas.

On November 28, 2013, participants were emailed the memoir to read and provided with instructions on how to log onto the online focus group discussion website. The participants answered four open-ended questions beginning December 2, 2013:

1. What are you thinking and feeling after reading this memoir?
2. What links, if any, have you made with your practice as a nurse?
3. What do stories, such as this, suggest to you about how nursing might approach caring for adolescent girls with eating disorders? What does this memoir suggest to you about how nurses work with families of adolescents with eating disorders?
4. What are your thoughts generally about the value of stories and memoirs as sources of information for health-care professionals? How might these kinds of narratives be shared with other health-care professionals?

In order to allow for work schedules and personal time, the online focus group website was open to the participants for a period of one month ending January 2, 2014. The participants were encouraged to answer the questions and respond to the comments posted by the other participants in the forum. The participants began posting on December 2, 2013 and engaged in discussions pertaining to their lack of education and knowledge on caring for adolescents with eating disorders. The participants also shared their feelings and judgements and their ideas around the role of memoir as a
source of information in nursing care. The discussions continued with regularity until December 22, 2013 when all discussions stopped, presumably for the holiday. Discussions resumed again on December 28, 2013 with numerous posts, continuing until January 2, 2014 when the website closed.

**Ethical Considerations and Procedures**

Melody consented to her story being told, and ethics approval was received from both The University of British Columbia and Interior Health on November 20, 2013. An email providing details of the study, eligibility criteria, and how to contact me for more information about the study (Appendix A), was sent out to all full time, part time and casual registered nurses on the pediatric unit of the hospital by the Patient Care Coordinator of the unit on November 22, 2013. Interested participants contacted myself directly and were emailed an informed consent form (Appendix B) that outlined the purpose and title of the study and type of information that would be gathered, as well as the risks and benefits of participation. The participants were made aware that their participation was voluntary.

Accompanying the consent form, the participants were given a letter of etiquette for the online focus group discussion (Appendix C). This letter described the manner in which participants would be encouraged to engage. Each participant was also offered a list of psychological/emotional professional supports if needed at any time during or after the study (Appendix D). The pediatric unit that was used as a site for data collection is a small unit; therefore it was crucial to ensure that the principles of privacy and confidentiality were adhered to firmly. To ensure confidentiality, participants were
assigned non-identifiable code numbers from the Centre for Teaching and Learning at UBC Okanagan to use for the online focus group discussions.

All information and data (stripped of identifiers) is being stored electronically at UBC Okanagan indefinitely and is password protected. All paper data will be stored for at least 5 years after publication of the study in a locked filing cabinet and then shredded.

**Analysis**

According to Creswell (2007) data analysis in qualitative research consists of “preparing and organizing the data, such as text data in transcripts, for analysis, then reducing the data into themes through a process of coding” (p. 148). In order for this to be achieved, I found Leggo`s (2008) five steps, which he titled RITES (Read, Interrogate, Thematize, Expand, Summarize), to be a useful approach to undertake a close reading of the transcripts. Using Leggo’s (2008) approach, I read through all of the participants’ responses a number of times in order to cultivate an understanding of their experiences. Next, I interrogated the narratives in order to identify significant statements or phrases related to my study topic and questions. This probing was intended to address the Who? What? Where? When? Why? How? and So What? of the narratives. While interrogating the narratives I began the process of formulating meanings for the significant statements, which were then organized into themes. The four themes identified at this stage were: The need for education; judgemental attitudes; emotions; and the value of memoir. Following this, I reflected on the themes allowing for deeper meanings and connections to surface.
I summarized the themes that were relevant to my research topic and provided a general statement about what was learned from the narrative. During this process I was aware, as per Holloway and Freshwater (2007), that writing is never neutral; it has political and ideological elements and reflects the subjectivity and the personal location of the researcher as well as that of the participants.

**Trustworthiness**

In all types of inquiry, according to Holloway and Freshwater (2007), researchers attempt to be trustworthy and honest, and they hope that the responses of participants are true; however, they know that narrators sometimes have bad memories, are muddled, or overdramatize for effect. Equally as important is the researcher’s lived experiences as she or he interprets the story. Given these realities it is important to understand that knowledge generated from research is provisional, meaning that it may be true for now, this moment, for here, for this locality and this culture. The truth cannot be absolute, certain, and forever. For qualitative research, a central concern in judging an inquiry is trustworthiness (Lincoln & Guba, as cited in Holloway & Freshwater, 2007) which is achieved by developing: dependability, credibility, transferability, and confirmability.

**Dependability**

If a study, that is the narrative of the researcher, is dependable, it should be consistent and accurate. This can be achieved through the audit trail in which the researcher describes in detail the research design, data collection and analysis, as well as the way he or she arrived at the conclusion (Lincoln & Guba, as cited in Holloway and Freshwater, 2007). The dependability of this study was achieved in my
comprehensive description of the study’s qualitative research design comprising two parts: memoir and an online focus group. Data collection and analysis were also thoroughly and accurately explained, as was the rationale for my conclusion.

**Credibility**

Similar to internal validity, credibility confirms the extent to which the researcher represents the social reality of the participants and the meanings they give to their experiences (Lincoln & Guba, as cited in Holloway and Freshwater, 2007). Great care was taken to maintain credibility by reading the transcripts several times to ensure a clear understanding of the meanings prior to organizing themes. I then cited verbatim the participant’s responses. An expert review was undertaken by sending the raw data and thematic analysis to my research committee. Following this the preliminary analysis was shared with the participants in order to ensure an accurate portrayal of their experiences.

**Transferability**

Knowledge and theory that are developed through research should have relevance for other settings. In this study I have provided a detailed description of the impetus and the assumptions that informed the research, how it builds on previous studies, how I gathered data, its location and participant selection criteria, and information about who participated. Whether a study is transferable is then decided by others who take into consideration these specifics and how they might be relevant for other settings which might be different, but are related (Lincoln & Guba, as cited in Holloway and Freshwater, 2007). Taking into consideration the particularities of healthcare professionals and practice contexts, the institutional structures of hospitals, at least
in North America are, to a certain extent, fairly similar. Therefore, the findings of this study could be relevant and applicable to other pediatric hospital units where health-care professionals provide nursing care for patients suffering with eating disorders.

**Confirmability**

The reader should be able to evaluate the research by the way in which the findings and conclusions achieved the aim of the study, and not the result of the researcher’s prior assumptions. There needs to be a transparent audit trail (Lincoln & Guba, as cited in Holloway and Freshwater, 2007). To uphold confirmability, I conveyed the precise ways and meanings used in this study, highlighting the entire process, citing accurately the participant’s responses, and presenting the findings reached in the aim of the study.

**Summary**

In this chapter, I have described the two key methods memoir and online focus groups which I employed in this qualitative study. This chapter also outlined the selection criteria and recruitment strategies, ethical considerations, analysis and the matter of trustworthiness as achieved through dependability, credibility, transferability, and confirmability was outlined (Lincoln & Guba, as cited in Holloway and Freshwater, 2007). In the following chapter I present my personal memoir. Chapter five will provide the results and findings based on the analysis of the data gathered from the online group discussions.
CHAPTER FOUR: MEMOIR

Eating Disorders: A Nurse-Mother Learns from Her Daughter’s Story

Sometimes God redeems your story by surrounding you with people who need to hear your past, so it doesn’t become their future

(Jon Acuff)

I remember the first adolescent patient with an eating disorder that I cared for as a nurse on the pediatric unit. She was angry, withdrawn and slept most of the day. When I asked her to step on the weigh scale that first morning, I had to check my facial expression to keep from showing the shock and horror I felt when looking at her skeletal frame. I could see her hip bones poking out against her hospital gown. Her legs were boney and emaciated. They looked like a pair of sticks. Her face was gaunt and pale. I remember being worried that she wouldn’t be able to stand on the scale as I was sure she would faint from weakness. As a nurse, I cared for many seriously ill and dying patients, but something about this adolescent and her diagnosis bothered me...actually it horrified me. This was self-induced. How could she look in the mirror and think she was fat? Why would someone purposefully starve themselves? Was this the fault of the media for showing thin models on every cover of every magazine thus reinforcing that only thin people are beautiful and acceptable?

My knowledge of eating disorders was limited to news coverage of the death of Karen Carpenter in 1983. She was a famous singer who died of complications from anorexia nervosa. I remember thinking back then ‘who in their right mind would starve themselves to death?’ My nurse training was not adequate in covering the topic of
eating disorders and, therefore, I struggled with the etiology and knowledge of how to best care for adolescents with this debilitating disorder. On the pediatric unit, I was required to sit with my patient with an eating disorder during meal times to ensure she didn’t hide food and that she ate everything on her tray within the allotted 30 minute time frame. This was a very unpleasant part of my day as I had to watch carefully that the patient didn’t try to hide food in her gown or napkin or ‘accidentally’ spill her drink...all ploys to consume less food. It usually ended with the patient yelling, crying, and refusing to eat. I was stressed and dreaded the end of the stipulated time because she was then held down by nursing staff that inserted a nasogastric tube and fed her cans of “Boost” through the tube to provide nutrition and calories. I personally struggled with the hospital’s eating disorder protocol as it was punitive rather than positive reinforcement and was devoid of compassion. It was based on rules and archaic policies, with harsh consequences if not complied with. Something seemed wrong with that, and yet I was obligated to follow the prescribed procedure. This was not how I envisioned myself as a nurse. To add to this stress, it was almost unbearable when the mother arrived on the unit to visit her daughter with an eating disorder. The tension in the room was palpable. I remember noting that the mother looked just as angry as her daughter. There was a chill in the air, no one talking, both sitting with their arms folded on their chests. Who was going to win the battle of food? Could the daughter outlast the mother or could the mother force her daughter to eat? I am sure the mother felt my silent judgement and disapproval as my body language was stiff and my questions clipped and short. I simply wanted to get out of the room as quickly as possible. I found it easier to talk to mothers of children with cancer. Those mothers were scared and
tense but lived on words of hope and accepted my hand and kindness. I felt like I was helping and making a difference.

As the nursing staff on the pediatric unit, we had numerous discussions over the years about our patients, mostly female adolescents, with eating disorders and what we believed was the central cause of the disorder. We had theories, not based on research but observation. Collectively, we noted that many of the mothers appeared cold, angry, and distant when they visited their daughter. We thought “no wonder the patient is starving herself to death having such an uncaring and unloving mother”. Our theory was that the daughters felt so rejected and depressed by the lack of love and care that they lost their will to live. Another theory was that the daughters were attention seeking. Perhaps the parents were so caught up in their own lives and working that the daughters were desperate to be noticed. Although many theories were considered, the most agreed upon was that the mothers were trying to control their daughters and the daughters were rebelling against control. Eating disorders appeared to be the result of an abnormal mother/daughter relationship. This led several of the nursing staff to have a wary and guarded relationship with the mothers of these patients. As well, a lack of education and understanding of eating disorders resulted in inconsistent nursing care. Some nurses were lenient with the patients and allowed them to leave small amounts of food on their tray while others were militant and demanded all food be eaten as ordered. Some nurses allowed the patients to go into the bathroom alone with the door closed to wash and dress while other nurses insisted the bathroom door be left open to ensure they didn’t vomit or exercise in order to burn calories and lose weight. This inconsistency not only caused confusion and resentment between the patients and the
nurses, but also created strife and many heated discussions among the nursing staff. We were filled with dread when assigned these patients. I found myself begging the nursing manager to assign me other patients that I felt competent to care for. However, if I was honest with myself, I had to admit I simply preferred to care for patients I felt were more worthy of care, instead of a patient with an eating disorder who did this to herself.

I held tightly to these judgments over the years until a fateful day in April 2005 when I discovered my own daughter Melody was suffering with an eating disorder. I was sitting in my home office and I could hear Melody downstairs through the heating vent vomiting in the bathroom. During the past few weeks, I had heard her several times. In the beginning, I pushed the thought of an eating disorder far from my mind as it didn’t fit with the theories discussed at work. I had been a good mother, not controlling and uncaring. I hugged my daughters often and told them daily they were loved. So, how could this be happening? It didn’t make sense. The thought was too painful to even consider. I remember staring at the heating vent and listening, but my heart was pounding so loudly that it drowned out the sound of my child hurting herself. I could feel my breathing getting faster. A lump had formed in my throat...and I couldn’t swallow as my mouth was suddenly dry. I remember my hands shaking badly. I wanted to run downstairs and tell her to stop it, but I didn’t. I couldn’t face it or her or the horrible reality of what was happening . . . instead I just sat and listened while I fought back tears. I felt alone, terrified and powerless, and I remember praying, God, please help me.
As an infant, Melody was tiny and beautiful. I loved holding her. With blonde hair and blue eyes, she looked just like her older sisters. As a toddler, she was very shy and quiet and clung to me when we went out. When her younger sister was born, she did not seem to adjust well, and constantly competed for my attention. Life was busy with four children and a step daughter, and I was often left alone to care for the girls as my husband was frequently out of town with his construction business. Our marriage struggled under the strain of raising children, which was compounded by physical abuse I suffered at the hands of my husband. When the stress reached a critical level, I made the decision to leave my abusive marriage. I had to work full time to support my family and often felt guilty that my daughters were spending many hours per week at a daycare centre and not at home with their mother. I constantly felt guilty when I got home after work as I was so tired that I looked forward to their bedtime so I could sit for a few minutes alone and relax. I was unable to go out with friends as I could not afford a baby sitter. Many nights I questioned the decision to leave my marriage. At times life was very difficult as I seemed to live in a permanent state of exhaustion. I was up at 5:00 a.m. each morning so that I could get myself ready for work, then fill all the girls’ pack sacks with everything needed for the day, get everyone up and dressed and fed, and out the door on time. After collecting the girls after work I had dinner to make, dishes to do, homework to help with, laundry, baths, and bedtime. The days seemed to run into each other with no light at the end of the tunnel. My ex-husband worked out of town and often could not take the girls for his court ordered weekend visitations, and therefore I spent many weekends at home with the girls after a gruelling week at work. I so badly wanted to sleep in or go shopping without all the children in tow, or simply lie
on the couch and read. I remember being so tired once that when I drove past a senior citizens’ retirement home and saw an elderly woman through the window reclining in a chair and watching TV, I burst into tears wishing that was me. I wanted to be that woman sitting in a chair with no schedule or responsibility. I just couldn’t imagine what it would be like to sit and not rush every day.

In 1996, the girl’s father passed away suddenly. My daughters were devastated, and I was emotionally unavailable to help them through their grief. I was exhausted and tired from working full time to pay bills and care for the girls. My daughters were forced to be self-reliant, and I know Melody struggled with this much more deeply than her sisters. She needed more of me than I could give. I don’t know if I ignored her cues or if I was too busy and drained to acknowledge them. As she grew, she became an anxious teenager and rarely stepped out of her comfort zone to try new activities or projects. She was moody and often yelled when things didn’t go her way. Her sisters avoided her as much as possible. When life became unbearable in the house I took Melody to our doctor. At age 16 she was diagnosed with an anxiety disorder. The doctor said she was sad about losing her dad and was afraid that I might die too. Her anxiety and fear were causing her to lash out at her sisters, me, and anyone else in her path. Oh dear God, she had been afraid of my dying and I didn’t know. How could I have missed this? Why didn’t I recognize the fear and worry in my own child? The signs were so obvious… She was very vigilant and hovered at my bedside whenever I was sick. Every time I rolled over in bed, there was her anxious, worried face looking at me and asking, “Do you want some water, Mom? . . . You have to eat the sandwich I made, or you won’t get well . . . Do you need some pills, Mom? . . . Mom, I think you
should go to the doctor.” I remember thinking that I could not show any signs of illness, tiredness, or weakness, as Melody became anxious, moody, and screamed at everyone in the house. I learned to plaster a smile on my face to show that I was well.

I got up from the desk in my office and slowly walked out to the kitchen and waited for Melody to come back upstairs. I was sweating and shaking. My heart pounded so hard that my chest hurt. I felt sick to my stomach. I started to panic as I heard her climb the stairs. Melody walked into the kitchen, and I murmured a silent prayer, asking for the strength, courage, and wisdom to confront her, but all I wanted to do was run away. I wanted to leave it for another time when I had more courage. I knew that once the words were said, there was no turning back. I wasn’t strong enough for this. Our family had been through enough. I tried to swallow past the lump in my throat . . . I blurted out, “Melody, we need to talk. I don’t want you to deny it because I know it’s true. You have been throwing up and have lost a lot of weight.” There, I said it. No turning back. I took another deep breath and swallowed and said, “I want to help you.” I vividly remember Melody staring at me for a moment and then bursting into tears and saying, “I have been trying to stop, but I can’t. I’m scared, Mom.” I was stunned! I was expecting yelling, stomping out of the room and denial as our patients on the pediatric unit have done—not a vulnerable, scared, and crying child. To my surprise, instead of my mother’s instinct kicking in, my nursing experience took over, and Melody and I sat and talked about the importance of eating and getting vitamins into her body. I was comfortable in my nursing role, and I needed comfort at that moment. She also agreed to sit at the table with me for all meals and wait 30 minutes before going downstairs or into a bathroom.
My lack of understanding of this disorder and my preconceived notions of the cause paralyzed me. I didn’t want to tell anyone as they would judge me and blame me. I especially didn’t want to tell our family doctor. She thought I had done amazingly well raising my girls alone, so how could I tell her? She would think badly of me and wonder how I let this happen. I didn’t want to tell my family, as they had always told me to slow down. They had encouraged me to spend more time with the girls and give them the attention they need. I would be blamed for Melody’s disorder. And I especially didn’t want to tell my nursing colleagues, as I would be one of those mothers we had negatively judged. I would be that uncaring and controlling mother who caused her daughter to rebel against the control and starve herself. With no one to share my fear and pain with, I became isolated and alone.

Ultimately I had no choice but to confide in our family doctor as Melody continued to struggle with eating. The doctor, although compassionate, had little to offer except to take Melody for regular blood work in order to watch for signs of stress on her body and bring her in for weekly weight checks. Rather than providing resources and treatment options she appeared to place the responsibility back on me due to my nursing experience caring for patients with eating disorders. This was disheartening. She had more questions than answers, which increased my despair and fear as I realized I was on my own to help Melody. I had secretly hoped that this would be behind us when all the relatives arrived for her high school graduation in the next two months, but I now wondered if it was possible. I desperately wanted everything to be okay. I needed everything to be okay. I didn’t want to face the judgement and criticism of my family. I had always kept the struggles and issues of raising my daughters alone to myself. I
tended to share their accomplishments and successes but rarely mentioned difficulties or failures to friends and family. To be honest I wanted others to see me as a perfect mother and a hardworking successful woman who singlehandedly raised her daughters despite all odds. I wanted to be approved of. I am not sure where this came from. Perhaps it began when as a child I was beaten by an abusive father for minor infractions and therefore tried hard to be perfect to escape punishment. I believe this continued in school when my grade one teacher strapped my hands for messy printing, and from that time forward I tried very hard to be perfect to avoid punishment. As a teenager working in retail, I remember being afraid of getting in trouble or being fired, so I worked hard and didn’t complain regardless of unfair treatment or working conditions. This behaviour brought the praise and reward I was seeking, and I believe this was the catalyst for the desire to achieve perfection in every area of my life including my family. Looking back I can see how I set myself and my family up for failure. It took years to realize that I could not control every situation and everyone.

Melody continued to lose weight despite my vigilance and control, and therefore we returned to the doctor for help and support. After a long discussion, the doctor suggested that perhaps this was a mental health issue, and Melody was referred to a psychiatrist. Melody was angry, saying she wasn’t crazy and I was making too big of a deal over her weight. She said I was the crazy one and should see the psychiatrist. Using this as leverage I told her I would go if she would. Several appointments were booked only to be cancelled when the day arrived. I was becoming more fearful and desperate, and when I threatened hospitalization Melody agreed to attend one appointment. She sat with her arms folded over her chest and stared at the floor in the
psychiatrist’s office. She would not discuss her eating habits or answer his questions, and after a few follow up appointments Melody refused to go back, saying the doctor was stupid and condescending. My suggestion to see a different psychiatrist was refused. As we drove home my body shook with fear and panic. My hopes had rested on the help of the psychiatrist and I now felt more hopeless than ever. What now? My daughter’s life was in my hands and I felt I was failing her badly.

I recall extended family members arriving for her high school graduation and discussing Melody’s thin body. I brushed it off by saying she was just stressed and found myself changing the subject whenever her weight was brought up. I was afraid of judgment if they knew the truth. When the graduation ceremonies were over and everyone went home, I was relieved, as the stress of lying and making excuses about Melody’s weight became exhausting.

Melody’s weight dropped significantly after her graduation and she began displaying bizarre behaviours like opening up cans of food and hiding them in cupboards. I discovered this when we developed a problem with ants. I screamed whenever I opened a cupboard, as ants were swarming all over the open food. The smell in the kitchen was sickening, as there was rotten and decaying food hidden behind dishes and cans. I remember finding garbage bags filled with empty containers and wrappers indicating that she was bingeing. What was happening to her? Why was she doing this? Melody was spiralling downhill and I didn’t know how to stop it. She refused to go to the doctor while I was forced to stand by and helplessly watch. My other daughters were disgusted and started eating meals at their friends’ homes. They had no patience or tolerance for her behaviour. I tried my best to clean the mess and
keep peace in the house, and although I didn’t blame them for wanting to get away from
the craziness, I experienced a feeling of loneliness and hopelessness like never before.
I spent hours crying while hunting for rotten food, cleaning the cupboards, and spraying the bugs. I was horrified, angry, and sad knowing what had become of my once vivacious child. I was at a complete loss as to what to do to help her, and to make things worse Melody wouldn’t talk to me about it. She said it was part of her eating disorder, and I had to ‘deal with it.’ I remember thinking “Is it possible to hate your own child”? I was ashamed of myself for thinking this as I knew in my heart that she couldn’t help it. I struggled with this thought daily as she became more belligerent in our conversations and continued to lose weight. I was losing control and I was terrified my daughter was going to die. I could not understand why she was doing this to herself and I felt enormous guilt that I was blaming her for the disorder. I felt even more guilt in believing that I was to blame for her eating disorder. My self-imposed isolation from family, friends, and help left me exhausted, overwhelmed, and depressed.

Our family life and Melody’s condition continued on a downhill path. In September 2005, she refused to go to our family doctor anymore, and I was powerless to force her as she was 18 years old and legally able to make her own health decisions. I was living with a seething anger and an overwhelming fear that I was losing the battle. My home was a war zone, and no one wanted to be there, me included. So I began working more and more hours per week. I just couldn’t face the horror at home. I had always found solace in work. I could help others and keep busy and not think about what was happening at home. At work I could pretend that everything was okay. I was good at that. I had perfected it over the years. I put a smile on my face and kept busy.
I avoided long conversations with my colleagues, and thus they didn’t appear to notice that anything was wrong. Emotionally I knew I was throwing in the towel but I didn’t have the energy to pray for help, as I was worn out physically, emotionally, and spiritually. Eventually I stopped crying, stopped visiting friends, and sank into depression. I felt as though I was in a black hole that was swallowing me up. I was numb, and if I wasn’t working I stayed at home in my housecoat. My normally spotless house was untidy. Dishes sat in the sink for days. I ignored the telephone when it rang as I just didn’t have the energy or desire to talk to anyone. I couldn’t concentrate on reading so I sat staring at the television without any thought of what was on. It was noise and an alternative to silence. Silence brought condemning and guilty thoughts. Silence brought paralyzing and fearful thoughts. When I wasn’t watching TV, I napped as it stopped the onslaught of thoughts and gave me some release from the hell I was living.

In time, work, which had once been my solace, became as much a nightmare as my home life. I especially struggled caring for girls admitted with eating disorders. They were so sick and skinny and I knew my own daughter was just as sick. The nurses weren’t aware of my family situation, and therefore I was forced to listen to their harsh comments and criticism of the mothers in silence. I felt even more condemned. Their judgement fell on me like a rock, reinforcing the feeling of guilt and causing me to further isolate myself. The 12-hour shifts left me both emotionally and physically exhausted. I would race out the door to escape the guilt and judgement I felt all day only to admit to myself that I didn’t want to go home. I would sit in the car in the hospital parking lot shivering from the cold, but unable to start the car. I couldn’t escape as
there was more pain and suffering at home. Oh God, what was waiting for me there? Would Melody be home? What mood was she in? Any comment or question could be misconstrued and blown out of proportion and result in screaming. I felt like I was walking on egg shells. I dreaded going home but was tired and had nowhere else to go, so with a sense of dread I would start the car. As I neared home, the knot in my stomach would get tighter. Sometimes I procrastinated by stopping at the store—anything to buy myself a few more minutes of peace. As I neared the house, panic would set in as I realized Melody’s sisters might be home. They had no tolerance for her erratic moods. They didn’t coddle her. They didn’t make excuses for her behaviour or disorder. They didn’t ignore the elephant in the room, and this intolerance often resulted in volatile fights and screaming, which I dreaded coming home to. My prayers on the way home many nights were: “Please God, don’t let the girls be home—I need peace and quiet tonight.” If I arrived to find the girls out and Melody in her room, I felt much relief. I could have my bath and relax in peace for a few hours before bed. I could ignore the impending doom for a little longer. Nursing took all my energy and I felt guilty that other families and sick children got my attention, care, and compassion. I seemed to know the right things to say and do for them. I made a difference. Why was it so difficult with my own sick child?

Melody continued on her destructive path and I continued ignoring it, until one cold November day, Melody walked past me. I gasped in horror. She was a human skeleton. Her face was gaunt and pale and I could see her hip bones and boney legs through her pants as she walked by. I clamped my hand over my mouth to keep from screaming out loud. She looked like death . . . I silently screamed, God help us! I ran
into my room and cried like I have never cried before . . . weeping, wailing, sobbing, which seemed to last for hours. With my heart breaking, I thought, “my daughter is going to die, and I can’t go on without her”. I began to pray and bargain the day away. “God, let me die instead or let her live, and I’ll devote myself to helping others suffering with this disease. This is my fault so whatever you want me to do, I will do it. Just please, God, don’t take her from me”. After my tears dried, I realized I had to stop burying my head in the sand and get the support and help she needed. I knew that if I didn’t she would die. I had held onto the shame and guilt for too long and my fear and selfishness nearly cost Melody her life. I decided that I didn’t care what my nursing colleagues would think of me. My daughter’s life meant more than their judgement. Whatever I needed to do I would do. I took a deep breath and phoned my pastor. I had nothing to lose and was ready to face condemnation and reproach, but instead of accusations and blame, I heard a compassionate voice on the other end of the phone. He listened patiently as I cried and admitted I was very scared and depressed. This was tough for me to admit as I was an intensely private person. Then, my pastor shared with me that his child had suffered with an eating disorder as well but was now fully recovered and doing well in life. I felt immediate relief. He completely understood my pain, fear, and guilt as he had experienced similar feelings. For the first time I felt supported. I felt hope. We booked an office appointment to talk more. After we hung up I cried more tears, but this time, not of fear and despair, but tears of hope and relief that Melody possibly could recover. Using my newfound courage I immediately phoned a close friend and asked if we could go for a walk. Through tears, I shared with her about Melody’s eating disorder. Holding nothing back, I bared my soul. She hugged
me and said, “You have been a great mom. This is not your fault.” Relief rushed over me. She didn’t condemn me or blame me. Why had I held on to this painful secret for so long? For the first time I realized that in order to help my daughter I too needed support and encouragement. My family and friends became my lifeline, and they built me up whenever I got scared or worried. I leaned heavily on them, but after a while I recognized that I was fragile and needed more support than they could offer, and therefore scheduled regular counselling appointments for myself. I found relief and peace and was able to be around Melody and discovered joy in doing little things with her such as walking the dogs or simply having a peaceful evening watching TV. Over time, as our relationship strengthened, I encouraged Melody to go back to the doctor, and when she finally consented, I was alarmed and was distressed to discover that her weight had plummeted to a dangerous level. Her blood pressure was perilously low, and her heartbeat was irregular and very slow. Because of this our doctor said she needed to be admitted to the hospital. I was shocked when Melody admitted that she had not eaten anything in three days and had had no water for over 24 hours. She was crying but refused to go to the hospital because she didn’t want to be force-fed or take medication. I was dismayed to realize I was powerless to make the decision as she was considered an adult. When we were alone the doctor told me that when Melody went unconscious, I was to call an ambulance and then she could be admitted. All I could think was, “Oh God...I have to take her home and wait until she is unconscious”? I sat in the doctor’s office crying and begging Melody to let me take her to the hospital, but she refused. I bargained and then threatened and finally begged, but all to no avail, and so with no other choice we left the doctor’s office. We sat silently in the car on the
way home. My heart was pounding with panic and with each mile closer to home I felt more alone, scared, and helpless than ever before. My mind was racing to find a convincing argument to take her to the hospital, but none came. After arriving home, I didn’t want to leave Melody alone for even a minute. We lay down on my bed and I held her in my arms. She was so weak and pale. I was afraid to close my eyes and sleep in case she would die before I woke up. I just lay there and stared at her. Tears were spilling down my face. I offered her a sip of water—no, I begged her to take a sip of water.

“I can’t, Mom, I can’t.”

“Please, Melody, just a little. Please . . . for me.”

“It hurts, Mom, I can’t.”

As I looked into my dying child’s face, my heart broke, and I tried desperately to hold on to my faith. I was watching my daughter die before my very eyes. As we lay there I cried and cried and prayed for God to save my daughter. I started to bargain again: “Please, God, let her live . . . I will do whatever you want me to do . . . I’m begging, please, God”! I kept vigil all night watching her breathe as she slept willing each breath to continue and praying for her heart to continue to beat. It was a long and agonizing night with every twitch a cause for panic. The hours were wretched. I was exhausted. In the early morning I slipped out of the bedroom and went into the living room. I didn’t want my sobs to wake Melody. A little while later Melody walked into the living room and said, “Mom, I need help.” She was frail but looked determined. I was shocked, hopeful, and scared to move or say anything that could cause her to change
her mind. I calmly agreed to help her, but on the inside I was jumping up and down with relief and hope.

Melody insisted that she didn’t want to go to the hospital but to a treatment center instead. She wanted to go where they did not force-feed the patients or drug them with pills. She wanted to go where they provided therapy to help her understand why she was doing this to herself. I had heard of an out-of-province treatment centre that had an excellent recovery rate for both anorexia and bulimia. Melody reviewed the centre online and liked their philosophy of care, which offered several hours of counselling per day in order to assist in physical, mental, and emotional healing. This was much different from our hospital program that included 30 minutes of counselling per day. The treatment centre also offered a collaborative, individualized, and supportive care plan with beliefs based on positive feedback rather than the punitive approach utilized by our hospital. Before she could change her mind, I phoned the centre and miraculously, they had a bed available. They said they usually have a waiting list, but because it was close to Christmas, one girl had backed out until January. They agreed to take Melody. The fee for treatment was high and they required a large deposit. It was not covered by my health care plan or my extended health care at work. Where was I going to get the money? Although I had no money in my savings account, I agreed to the terms so Melody could get registered. I would find the money somehow. I decided I would do whatever it took to save my child. I managed to scrounge the deposit and sent it the next day.

As the day approached for Melody to leave, she was both excited and scared, but promised she would stay until she was well. I could not go with Melody to the
treatment centre because I had work obligations with no replacement on short notice. Maybe subconsciously, I was too afraid to go and see other anorexic girls—too real, too close to home. Maybe I was simply too emotionally exhausted to cope with the centre. I drove Melody to the airport on a cold, snowy morning at the end of November. My fear grew that she would back out, but I was equally as terrified that she would get on that plane. Melody was so frail and skinny that people in the airport stared at her when we checked in, and I wanted to yell, “Stop staring and mind your own business!” How can people be so insensitive? I was raw and had little tolerance. As soon as Melody received her boarding pass, I hugged her and quickly turned to leave—it was too painful to prolong the good-bye. Just before I went out the door, I took one last look at her. Panic and fear overwhelmed me. Was this possibly the last time I would see her? Was she going to die? Suddenly, I didn’t want to leave. I kept thinking, why am I sending my frail, sick daughter away to get help all alone? I should be going with her! Why didn’t I take a leave from work? All at once, I hated my job. I hated leaving Melody. I hated everyone and everything at that moment, but I especially hated myself. I pushed these thoughts from my mind and smiled bravely at Melody, whispered that I loved her, and turned to walk out of the airport. Before I reached my car, the tears started to flow. I cried so hard I couldn’t see well enough to drive. I just sat in the cold car in the parking lot, and tears poured like water down my face and onto my winter coat. I couldn’t pray as I was too grief-stricken. “What a terrible mother you are” ran through my head over and over. I was paralyzed with fear that I would never see Melody again and wanted to run back into the airport and hold her and never let her go. I wanted to tell her I was sorry that I didn’t take care of her like I should have. I wanted to tell her I was sorry that
I failed her and had to send her away to get the help she needed. When I drained the last tears in my body I started the car and prepared to leave my daughter. Despair and helplessness filled my body and soul. I was somewhat thankful to be going to work as I could not imagine going home alone as I would have too much time to think and the silence would condemn me. At the hospital I would be busy caring for other sick children and not have to think about my own sick child. It would be a reprieve.

But there was no reprieve on this day on the pediatric unit because an adolescent patient with an eating disorder was admitted. It was extremely difficult listening to the unkind comments from the nurses regarding the mother of the patient. How could a mother let this happen to her daughter? How did she let it get so bad? Why do the mothers look so angry and cold? Why don’t they hug their daughters? Why do they bother coming in? They should just stay away. I felt more and more condemned with each remark but unable to speak up. I was one of those mothers they were talking about. As a nurse I had had these same thoughts and used to ask these same questions... as a mother of an adolescent with an eating disorder I now had a better understanding and perhaps some answers. I no longer ascribed to my old beliefs and found myself looking differently at the mothers. What I previously considered a cold and uncaring stance, I now recognized from personal experience as fear, exhaustion, and being overwhelmed. I realized that these mothers most likely love their daughters as much as I love mine, and this revelation turned my judgment to compassion and understanding. This left me in the unenviable position of being both a nurse caring for patients with eating disorders, as well as a mother of a daughter with an eating disorder. I believe my professional experience as a nurse contributed to my decision as a mother
to keep my daughter’s eating disorder a secret and isolate myself from help and support. The notion that mothers were to blame for the disorder paralyzed me from getting help. I did not want to be labeled as a controlling and cold mother. I did not want to be considered a terrible mother. Although I was eager for the work day to end so I could get away from the negativity, I dreaded going home alone. This was compounded with worry about how Melody would manage her flight connections in her weakened state. After arriving home I took a deep breath and phoned the treatment center. Oh God, I hope she made it. I hope she is safe. I hope they can help her. I was thankful to discover that Melody had arrived safely and had eaten some dinner. That was the best news I could have received. She had been refusing food for days at home. I think both Melody and I were ready for change and recovery.

While Melody was away at the treatment centre, I began to cope and live again with the support of family and friends. I also joined an online support group for families of children with eating disorders, read books, and had weekly counselling appointments and in time I was able to accept that I was not to blame. Melody had an anxiety disorder that triggered the eating disorder. She needed control to give her peace and settle the anxiety. The eating disorder, although maladaptive, was the only control she had in her fearful world. The treatment centre helped Melody recognize this as well. As life stabilized, my other daughters spent more time at home, and together we began our healing process. It was difficult as our emotions were raw and injured. I knew they were hurt and sad and scared for Melody so we worked together through the pain. It wasn’t easy and many times our discussions ended in yelling and someone stomping out of the room, but in the end we discovered the joy of forgiveness and decided we
were worth saving. During this time I was also phoning Melody and she was begging me to come home. She said the girls there were crazy and way sicker than her. She said she didn’t belong there. It was hard as I wanted to protect her and bring her home, but I was firm and encouraged her to focus on her own healing so she could come home well. Many times she called to complain about the staff as they pushed her to challenge her anxiety about control and to eat. However, as the weeks went on she settled into the program and stopped complaining about everyone and everything and worked on herself. She fought through control issues and fears of weight gain. The intense therapy was very hard for Melody and there were many emotional crises at the treatment centre, however she slowly began to win the battle. The therapy taught Melody how to address and cope with her anxiety and fears. She developed tools to stop the maladaptive behaviour and practice healthy ways of responding. One of the conditions for discharge from the treatment centre was for Melody to attend weekly appointments with her family doctor for weight checks and blood work, and with a nutrition counsellor specializing in eating disorders to help prevent a relapse. She arrived home in January 2006 with a healthy weight gain and a much better outlook on life. There were struggles initially and times when I panicked if Melody skipped a meal or became ill and vomited. However, over time my fears and worries decreased as Melody continued to gain weight and remain healthy.

Melody met a wonderful young man, and four years later they married. She was a glowing bride and looked beautiful in her wedding gown. Family and friends came to show their love and support during this blissful time, and I cried tears of joy. Melody and her sisters are very close now. They look forward to holidays to get together, and
they talk frequently on the phone. I am so proud of the work she has done to get well. She is happy within herself and who she has become as an individual, as well as someone who is married and the mother of two healthy beautiful boys. Her husband is incredibly supportive and loves her as she deserves to be loved.

I have had time to reflect on the experience of my daughter’s eating disorder. The journey taught me that my preconceived notions of the cause of eating disorders created a destructive home environment. Feelings of anguish, guilt, shame, and fear caused me to isolate myself from support and help. I became exhausted, overwhelmed and depressed and I believe this seriously affected Melody’s recovery. The healing process began when I opened up and looked for help for both Melody and our family.

As a nurse I now have a better understanding of the importance of supporting patients with eating disorders and their mothers. Nurses need to understand that a mother’s flat, stern, or cold expression may be the result of sustained fear, worry, exhaustion, guilt, and depression. By blaming the mother for the disorder we actually contribute to the disease and inhibit recovery by adding to her isolation and guilt and thus undermining an integral resource for the daughter’s recovery. I now recognize that lack of knowledge and understanding of the cause of eating disorders creates a toxic hospital environment that stigmatizes and ostracizes mothers. Negative interactions leave mothers feeling isolated and unclear about their daughter’s prognosis. Nurses must develop an environment of support, compassion, and collaboration. Taking the time to listen to a mother’s story, concerns and questions and including them in decision making can help to develop a trusting relationship, which in turn can have a positive effect on the adolescent’s recovery. My own experience has taught me that mothers
must be encouraged, supported, and included rather than blamed and judged for their adolescent’s disorder.
CHAPTER FIVE: ANALYSIS AND FINDINGS

This chapter provides the findings of my analysis of the data gathered through the online focus groups. The themes are considered in detail in regards to the responses from the four open-ended questions posed on the online focus group forum:

- What are you thinking and feeling after reading this memoir?
- What links, if any, have you made with your practice as a nurse?
- What do stories such as this suggest to you about how nursing might approach caring for adolescent girls with eating disorders? What does this memoir suggest to you about how nurses work with families of adolescents with eating disorders?
- What are your thoughts generally about the value of stories and memoirs as sources of information for health-care professionals? How might these kinds of narratives be shared with other health-care professionals?

The online questions brought about a vigorous discussion with responses mirroring my own thoughts and feelings.

Analysis of the data retrieved from participant responses to the online questions revealed several key themes but overall my colleagues expressed a strong desire to provide excellent care to patients and their families suffering with eating disorders. Acting on that commitment was made difficult because of a number of barriers. In the following sections I expand on participants' views in relation to four major themes: the need for education, judgemental attitudes, emotions, and the value of memoir. The findings of the analysis were sent to the participants and they responded affirmatively. The participants have been given pseudonyms.
The Need for Education

A strong theme commented on by all participants was the need for education. Within this overarching theme, several subthemes emerged. Participants often referenced their emotions (I explore more on this issue later in the chapter). They also spoke about the need for specialized training, particularly in the area of psychiatric illnesses. They described how they lacked the appropriate tools and resources such as care plans. Participants pointed to how the hierarchy between nurses and physicians also impacted their ability to provide quality care, and how the different approaches towards eating disorders used by health-care professionals leads to confusion on the part of both nurses and patients and their caregivers.

Emotions

All participants noted the lack of knowledge and education about eating disorders, which led them to feelings of fear, confusion, frustration, sadness, and remorse. Colleen discussed how a lack of knowledge left her feeling frightened of doing and saying the wrong thing:

We as nurses are still unsure of how to approach these patients and their families.
We are really not given any direction on how to begin caring for patients with eating disorders. We are scared to have these patients because we don’t know what to say...we are scared we will say the wrong thing.

Carla also expressed her dismay at the absence of knowledge and proper resources: “It makes me sad to think that we do not have the proper policies and procedure in place.” Despair over the educational inadequacy persisted throughout the discussions as the participants worked to identify and verbalize what they needed to
alleviate their distress. Likewise, Jane despaired over the lack of education that has caused her to feel “saddened and ashamed of the care that is provided to patients with eating disorders and their families.”

**Specialized Training**

While the call for more education was expressed by all participants, they drew attention to how little specialized training they receive, particularly in the area of psychiatric illnesses. As Carla noted, “nurses do not get enough education on eating disorders, as well as any psych illness. We are expected to provide care for the youth with psychiatric illnesses yet have little education.” Carla echoed the views of many participants regarding the need for specialized training, “We as nurses have a lack of special knowledge in regards to dealing with eating disorders. I feel that this lack of education and knowledge leads to the inconsistencies in care.” Similarly Karen noted that poor care was the result of lack of knowledge and believed that with better training the outcomes would be much improved:

If we, as nurses in this community were offered specialized training to deal with this illness our outcome here would be greatly improved. We can only be therapeutic and understanding if we truly know what we are dealing with. I have no specialized education in handling eating disorders and thus I struggle with it.

From my personal experience as a health-care professional, I am aware of the lack of resources such as funding, support, and qualified personnel to provide the education needed for these patients. Frances pointed out that this lack of skills and knowledge was not only frustrating but also harmful. As with other participants, she suggests that improved specialized education would alleviate this suboptimal care standard:
If we could get more education on this illness, we could do a better job of caring for these children. I feel eating disorder patients slip through the cracks of our system and we actually do more harm to them, upon leaving the general paediatric ward. It's specialized, and requires much education and a treatment centre does a better job in my opinion.

As Jane observed, there was strong consistency amongst participants regarding the need for education and specialized training:

We all seem to be in agreement that nurses need to have more EDUCATION! As a staff nurse … I have never been offered an in-service on anorexia or any other mental illness. I would welcome any education to help me in my practice. I would love to know more about the program in Manitoba and how we could use some of their practices.

Frances felt that nurses were there to provide physical care but ignored patients’ psychological needs, “Nurses do not get enough education on eating disorders as well as any psychiatric illness. We are expected to provide care for the youth with psychiatric illnesses but have little education.” She was the only participant to indicate she had received some specialized training:

I was fortunate to attend a one day workshop on eating disorders which helped me to better understand the disorder. One thing I remember learning was that it was more a self-esteem issue than anything to do with food. I have always felt great compassion towards these girls with their struggle.
Better Resources and Tools

Several participants noted lack of resources. Samantha believes that stories included in conferences and in-services, rather than just clinical facts, would provide a valuable resource to nurses on the pediatric unit:

I feel that there could be more conferences and in-services offered to help nurses in expanding their resources for caring for patients with various illnesses. If stories like this, rather than just clinical facts were offered during these sessions, it might change the perspective of nurses caring for these and other patients.

Other participants identified the issue of out-dated resources. As Colleen noted:

We still use a care plan that was devised many many years ago! It is so backward thinking … We are not given the tools to help us work through these admissions and help these patients begin their journey towards recovery.

Colleen links the poor preparation of nurses with respect to care of patients with eating disorders with nurses’ anxiety:

I do not think that nurses on the pediatric ward are well equipped with what we need to ensure quality care for these patients and their families. I think most of us (not all of us—many nurses dread caring for these patients) have good intentions for these patients, but I really feel that there are not enough resources in place for us to do this. We need more support, more information, a more focussed, individualized way of providing care for each of these patients.

As a health-care professional on the pediatric unit, I am also aware that the current eating disorder policy and procedure manual is outdated having been developed over 20 years ago. This further speaks to the influence that the hierarchal system has
over those at the bedside and how that system determines hospital policies and procedures.

Hierarchies of Care

Another element raised by participants, one that impedes their ability to provide good care, is the hierarchal working relationships between physicians and nurses. Participants like Frances noted this gap and its impact on providing good care:

We are taught basically to say nothing and let the psychiatrist talk with these patients, yet we are the ones at the bedside day and night. The patients therefore lack the care they should be provided. It must be frustrating for the families and as a nurse I find it frustrating in that I don't feel like I have the tools to help them understand their struggles.

Colleen echoed this frustration with the system, “There does not appear to be any support from the upper levels of the institution to address the inconsistencies in care.” From my personal experience as a health-care professional, I agree with my colleagues given that we don’t have the specialized education to care for patients with psychiatric illnesses, we are told to leave this care to the psychiatrist.

Inconsistent Approaches

While all participants called for more education and training, they also raised another important issue, which was the lack of agreement amongst health-care professionals regarding the best approach to eating disorder care. Calling for more education then will be hampered if this issue of diverse and competing approaches is not addressed. As Colleen notes:
There are so many inconsistencies in the care for these patients. All doctors and nurses have their own approach and as such, patients are confused and unsure of what to expect. I think we all try to do a good job, but many of us do not know where to start.

Susan talked about the importance of honesty and using a consistent treatment approach:

I think that it is very important to be very honest with these patients and their families so that they know what and how things are going to unfold. It is important that we are all on the same page through their treatment. It does not help these patients and their families to keep changing the plan.

Frances discusses the repercussions of inconsistent care: “They [patients] can be manipulative and if we do not have a specific and well documented plan, each nurse does things a little differently and the patient learns to play one against another.”

**Judgemental Attitudes**

Participants identified the connection between lack of education and being judgemental, and its effect on patient health outcomes. Linked within this theme were the subthemes: respect, understanding, compassion, empathy, and blame.

Colleen reflected on how the previously accepted behaviour of passing judgement on families and patients with this disorder was not acceptable:

I am absolutely guilty of passing judgment on families (not just mothers) of adolescents with eating disorders. I consider myself a very kind, respectful and compassionate nurse. Being aware of how eating disorders affect patients and families is helping me provide better care with fewer judgements. I have
historically used the excuse - well, I'm only human and that is what we do. We judge. I will do a good job, but if I form judgments every now and then that is ok. But it isn't ok.

That this memoir stood to raise awareness to many of the participants in this study brings to light the surprising attitudes that can be adopted by even the most compassionate health-care professionals when they are repeatedly met with conditions in which they feel unsupported. The resulting discussion stressed the importance of being understanding and empathetic rather than judgemental. Susan lamented the harsh judgements of health-care professionals:

I found it sad that as nurses we can be so judgmental and really unaware of this until we are put in a similar situation. I think that as a profession we can and should provide much better care for both the patients and their families. I think that slowly we are getting better at improving our care...I think that there is now better understanding that in order to build a trusting relationship we have to all be on the same page. The most important thing is to treat every individual case differently and be empathetic to what they are and have gone through.

Samantha made links between the established judgemental nursing culture and a lack of understanding of eating disorders. It is curious that the participant identified this attitude as a coping mechanism within nursing:

Not that I condone the slander of mothers or families of children with any medical or psychological struggles, but this seems to be the established culture that has arisen whenever nurses are at a loss to understand the behaviour of individuals that they are working with. I believe that this is a coping mechanism that some
nurses put in place in order to be able to reconcile this behaviour in some way that they can cope with it. I have heard this kind of negativity towards the families of patients with eating disorders and have been tempted to join in myself at times when these types of situations become too tense.

Participants, such as Karen, spoke about her own attitudes towards this illness, to parents of adolescents with eating disorders, and its related stigma. She found the memoir had motivated her to change and develop a more caring approach:

I related to the beginning part of the memoir when the writer was expressing that she found it difficult to care for patients with eating disorders because she felt that they were doing this to themselves, and more physically sick children were more deserving of her care. I have admittedly felt like this before while caring for patients with eating disorders. Also, the fact that the mothers seemed distant and cold towards nursing staff, and even their own children. Nursing staff need to be able to form a rapport with the family/patient to be able to empathize and work well together for the best patient outcome. And that is hard to do when there is a stigma involved. Stories like this memoir need to be shared with nurses caring for patients with eating disorders so that we can begin to understand different perspectives.

Jane emphasized the importance of being non-judgmental and the delicate nature of gaining trust with patients and their caregivers, in light of their fear:

Stories like this suggest that nurses have to approach caring for adolescents with eating disorders very delicately. Nurses need to gain trust by displaying a caring,
accepting, and non-judgemental attitude. Nurses have to remember how scared these patients and their families are.

Participants also discussed the importance of compassionate and empathetic approaches. After reading the memoir, Carla was reminded that everyone has a story of personal struggle and that health-care professionals need to try to understand and develop relationships with patients and families rather than judge and blame them:

I think memoirs and stories such as this remind us that these "cold, stand-offish" mothers are also physically, emotionally, and spiritually drained just like these girls, and these stories force us to think twice before judging their demeanor. I think that we need to enter into these relationships with these patients and their families with compassion, empathy, and attempt to understand their personal struggles.

The theme of judgement persisted throughout the discussions as did the importance of being aware of such biases. Susan stated that the last thing patients and families need is more of the same struggles that they are facing at home to be compounded by health-care professionals:

We did go into this profession to help others. It may not always be easy but it is very important to be aware of and put aside our own personal judgments and biases. You do not always know what goes on behind closed doors. What these families are struggling with is something that they have been struggling with for a very long time and the last thing that they need is more negativity and criticism from us.
Emotions

As noted in the section on need for education, many participants expressed a variety of emotions such as sadness, shame, anger, and frustration linked to the lack of proper education and training about providing care for patients with eating disorders. They also commented on the emotional responses of adolescent patients with eating disorders, which create challenges for providing care. Such patients are often admitted for treatment against their will and are therefore fearful, angry, and resistant, leading to an “us against them” relationship between health-care professionals and patients. Such antagonistic relations generate even more emotional responses that hinder patient recovery. Jane spoke to how she’s learned about the frustration and fear that families feel:

After reading this memoir I am thinking and feeling many things. I feel saddened and ashamed of the care that is provided to patients with eating disorders and their families. I understand the frustration and fear that the parents have. I feel like that too when dealing with some of these patients. Patients with eating disorders can be difficult to deal with because they generally don’t want to be helped and they are often angry and manipulative. It is hard to care for a person that is angry at you.

Colleen identified with the memoir author’s feelings of anger towards the families and patients with eating disorders and found the memoir helped her to acknowledge these feelings that have been below the surface:

When a patient with an eating disorder is on the ward, some of the most prevalent feelings that I encounter within myself are those of anger - towards the patient and
the parents. And I do find myself asking some of the questions that are mentioned in the memoir....how could they have let it get this far? What happened to her to lead to this disorder? What have her parents done to address this issue up to this point? These feelings do not dominate the care that I provide and I think often they are just under the surface...I do not really consciously acknowledge these feelings, but I recognize that they are there.

The majority of participants expressed uncomfortable emotions like fear, sadness, frustration in relation to reading the memoir and recalling their experiences with patients with eating disorders. Susan found it “sad that as nurses we can be so judgmental and really unaware of this until we are put in a similar situation.”

It was encouraging to find one participant, Samantha, who spoke of how the memoir helped provide her with a better understanding and more empathy for families of patients with eating disorders:

After reading this memoir, it provided me with a more in-depth empathy for what the mothers of the children with eating disorders go through... I try as a nurse to be empathetic and to imagine what it must be like for them to be in that situation. However, I find that dealing with eating disorders is so much different than anything else that most parents deal with at home. It does have medical aspects that can be seen and tracked, but the psychological block that occurs in these patients must be just as, or more, distressing than the physical symptoms for these parents. Reading this memoir gave light to how deep and debilitating that struggle can be for parents.
Participants, as has been already noted, found much value in reading the memoir and in the next final section, I turn my attention to that discussion.

**The Value of Memoir**

There was much agreement by participants that the memoir was an excellent educational resource for health-care professionals, noting how stories can help nurses look beyond the category of eating disorders to the person experiencing the illness. The consensus was that stories can be an educational resource for learning that is not transactional or didactic; it builds relationships and encourages critical reflexivity in the reader. Specific stories, participants argued, should be shared with other health-care professionals to increase awareness, knowledge and understanding of families’ and patients’ experiences. With respect to the value of memoirs, several subthemes emerged including: deeper understanding and alternative view of eating disorders; eating disorders impacting the entire family; and reader reflection of experiences.

**Deeper Understanding and Alternative View of Eating Disorders**

Rather than focusing solely on the illness, participants realized that stories allow for a deeper understanding and relationship with families and patients with eating disorders. Participants such as Karen saw value in knowing more about the patient’s experience as a meaningful way to provide nursing care:

> Stories and memoirs such as this one are so valuable to health-care professionals. It makes you think more about the PERSON experiencing the eating disorder, not so much the actual disorder itself. We are getting a first-hand account of what it is like to be going through it as a family member.
While many health-care professionals pride themselves in being kind, respectful, and compassionate, these participants identified how this is difficult to achieve with this patient population. In addition to memoir bringing a meaningful element to nursing, participants such as Susan also discovered that the sharing of stories is also important for personal and professional growth:

I think that it is important and very valuable to share these stories. It is only through others’ experiences that can we learn what works and what does not. It allows us to grow both as professionals and individuals. Understanding their stories is key to helping them overcome illnesses.

There was much discussion about the difference in providing nursing care for physically versus psychologically ill patients. Adding to this discussion, Karen noted how the memoir had helped her realize how ‘fixing’ the problem dominates the provision of care. An alternative approach, she realized, is needed when dealing with patients with eating disorders:

Stories and memoirs are valuable in the fact that they make us, as nurses, understand what patients and their families are going through in a completely different perspective than what we may preconceive. Sometimes in an acute care area such as pediatrics we have blinders on and really just want to fix the problem with a medication or a surgery but obviously this is impossible with an illness such as anorexia.

Adding to these thoughts, Samantha observed how stories can interrupt the process of medicalizing patients and help nurses to personalize care:
I highly value stories and memoirs when it comes to sharing this sort of information. I feel that these types of memoirs add a personal aspect to the care of these patients, helping the nurses not to de-sensitize and "medicalize" themselves in their view towards patients and families.

**Eating Disorders Impacting the Entire Family**

The value of memoir not only allowed for a deeper understanding and alternative view of eating disorders, it shed light on the magnitude of its effects on families. Karen learned from the memoir how as a nurse she needs to work with whole family and be empathetic and supportive towards these parents:

In reading this memoir it really brings to light the fact that the patient is not the only vulnerable person requiring help. The whole family is affected and they may not even realize how badly their feelings of guilt and devastation are making them avoid the support that is truly needed. We can definitely approach the topic and let the family know there is no shame in dealing with this sort of illness and that help is an essential part of treatment and healing for everyone involved.

Jane, like many other participants, found that the memoir enlightened and reminded her that eating disorders touch many families who face significant challenges in seeking treatment. For her, the memoir could help to motivate health-care professionals to be supportive of families:

The memoir shows how eating disorders can happen to anyone’s daughter. It is heart wrenching to read how hard this disease is on parents. It illustrates how difficult it is for parents to get their adolescent to accept help. The memoir should
motivate health-care professional to work harder at helping these patients and their families.

**Memoirs and Reflexivity**

The notion that memoirs are powerful ways for readers to reflect on their own experiences and emotions is well endorsed by the participants. It was clear from participants’ responses to the memoir that the memoir helped them pause and reflect back on their own nursing practice. For Colleen, personal stories were powerful because they encouraged a relational, rather than clinical, practice:

I believe stories play a HUGE role in helping nurses remember why we are doing what we are doing. We so often see our patients as "the anorexic in room 34" or "the appy [appendicitis] in room 35". Reading personal stories like this are so powerful in helping us understand the lived experiences of those for whom we care. If we can't understand what the illness or diagnosis means for each patient, how are we supposed to provide care that is meaningful for that patient? If I don't know that my patient has lost her father suddenly and is scared to death that her mother might die too and that she feels out of control when thinking about these things, how am I going to help her begin to address these worries and start towards recovery. How do I find these things out? By asking! I think we are always so afraid to interact with these patients that we miss out on obtaining valuable information.

In addition to these comments, Karen believed that families would also benefit from reading memoirs because they provide hope and comfort as they support their adolescent suffering with an eating disorder:
I think that memoirs such as this would be beneficial for the family members of a patient with an eating disorder. It may give them hope to know that other people have gone through the same thing.

**Ways to Share Memoir**

After establishing the value of memoir, the participants carried out a dialogue on the various ways in which memoirs could be shared with other health-care professionals. There was consensus that memoirs would be powerful tools to use in educational workshops, nursing programs, online programs, conferences, in-services, and lectures at the hospital. Jane saw the memoir as particularly useful for teaching about mental health: “An in-service/lecture at the hospital, it could be a part of the mental health component in the nursing program; it could be sent to health-care professionals to read.”

Samantha also found much value in memoir as it provided a different perspective about the illness compared with traditional clinical education approaches:

I feel that there could be more conferences and in-services offered to help nurses in expanding their resources for caring for patients with various illnesses. If stories like this, rather than just clinical facts were offered during these sessions, it might change the perspective of nurses caring for these and other patients. Colleen concurred that memoirs could be important resources for workshops; she also suggested that nurses could write their own stories of providing care:

I think that these narratives could be shared with others in the form of workshops for people who care for certain patient populations. I think nurses should be
encouraged to share their experiences with others so that we can learn how others provide care and obtain information.

For Karen, if memoirs were part of continuing education efforts, she would gladly participate on her days off:

Workshops, special education sessions, and online learning to share memoirs like this would be beneficial to health-care professionals. I know I would be more than happy to attend an education session on a day off to better understand and hopefully be better able to care for a child with an eating disorder.

**Reflections and Summary**

I greatly appreciated the open and honest dialogue from my participants about their past experiences in caring for adolescents with eating disorders, and how candid they were in describing their judgemental attitudes. The emotional quality of their responses was also notable; their anger, sadness, and frustration when providing nursing care to families and patients with eating disorders mirrored my own. It was hard to believe that we all felt the same and yet kept our feelings and concerns from each other—suffering in silence. We often complained about being assigned to this patient population, but there were never any open discussions as to why.

It was startling to see the substantial resemblances between the responses and concerns in this current study as those made by health-care professionals in studies as early as the 1990s. I asked myself these questions: Why has nothing changed? Why are health-care professionals still struggling with a lack of education and understanding of eating disorders? And why are we so judgemental towards families and patients with eating disorders? These questions will be further explored in the next chapter as I
consider the results in light of the reviewed literature. I know that health-care
professionals generally consider themselves kind, caring, and compassionate.
CHAPTER SIX: DISCUSSION

The overall goal of this research was to explore the value and impact of a narrative approach, through memoir, on the development of health-care professionals’ understanding of how eating disorder impacts families and the importance of using a collaborative approach—one in which health-care professionals collaborate and partner with families of adolescents with an eating disorder. In my memoir I shared my struggles of caring for a daughter with an eating disorder, including my initial shock and fear of reaching out to others because of the stigma of this disorder. I was aware, as a pediatric nurse myself, of blaming and judging practices among health-care professionals; these were practices in which I also had engaged prior to my daughter’s illness. I then disseminated that memoir to a small group of nurses, who worked in the same pediatric unit in which I am employed and were part of my professional network. It was my belief that including my colleagues in my study would enhance my ability to see the impact of this memoir, and the participants would have many opportunities to engage with me and raise questions about the study. Through an online discussion forum, the participants commented on the memoir and its impact on them. In their responses participants shared their frustrations with the lack of education and resources, which limited their knowledge and understanding of eating disorders. They shared their emotional reactions to caring for patients with eating disorders and also the educative value of the memoir.

In this chapter I return to my research questions in light of the findings discussed in the previous chapter and the current literature. I also reflect on my experience conducting this study. My main research question was what contributions arise from
writing a memoir about the impact on a family of a female adolescent with an eating disorder and the family’s encounters with health-care professionals? My sub-questions were a) what is the outcome of sharing that memoir with health-care professionals? and b) how can this memoir contribute to a collaborative approach to treating eating disorders that respects and includes the family?

Act I: Writing the Memoir

As noted, my initial interest in this topic began when my daughter developed an eating disorder and I did not know how to help her. My limited understanding of eating disorders was based on conflicting information in the media and my exposure to patients with eating disorders in the pediatric unit where I am employed as a registered nurse. After I realized my daughter had this disorder, I became afraid, anxious, and depressed. I felt completely alone and carried feelings of guilt and shame that I had somehow caused this to happen to my daughter. The literature revealed that the majority of families caring for a person with an eating disorder felt the same (Whitney et al., 2005). Their stories were similar to my own. This was evident in a study lead by Kyriacou et al. (2008), who discovered that families of persons with eating disorders, particularly mothers, had high levels of distress, depression, and anxiety resulting in an impaired quality of life. Whitney et al. (2005) found that families displayed sadness, distress, fear, anger, and hostility, and expressed self-blaming emotions such as guilt, failure and inadequacy.

Compounding these feelings of mine was the fact that my family doctor had limited understanding of the disorder and therefore was unable to offer much information and the treatment needed for my daughter to recover. The doctor was
aware that I was a pediatric nurse and assumed that I was familiar with the eating disorder protocol from the hospital and asked if I could implement a similar regime at home. I left the doctor’s office discouraged, scared, and frustrated with the lack of understanding and help I felt I had received from this medical professional. In that moment I felt alone in my quest to help my daughter. These feelings seemed validated after reading the literature and discovering that perceived lack of understanding of eating disorders from medical professionals was a common experience (Gilbert et al. 2000).

After my daughter recovered from her eating disorder, I wrote about my experience as a way to make sense of what happened. My mind was still confused and unsettled and I needed an outlet. Writing helped me look at the experience from a different perspective. In the retelling of the story I gained a more objective understanding of our journey. I was able to look at my story, literally look at it, and see how I had focused on my failings as a mother and allowed myself to feel guilt. Reflection helped me to realize that I was not the reason my daughter developed an eating disorder, and the sense of peace I felt from that was overwhelming. The fear, guilt, and anger somehow lost its power. Through the process of reflexivity, I realized my story had value and my experience could be helpful to others. As I cited Conway (1998) earlier, she best described the purpose and goal of memoir writing, stating, “Every autobiographer wants to persuade others to learn from her or his life, take up some important cause, follow a new spiritual path, be aware of particular hazards, and develop a new moral sense” (p. 16). After I shared my newly found understanding with my nursing colleagues, they were eager to read my memoir. According to Frank (2002):
This linkage of personal troubles and public issues, which is the foundation of politics, begins in the cultivation of personal stories. People can move from experience to politics only when their experience is narratable to themselves and others, and thus made legible. (p. 8)

I was amazed to hear that they cried after reading my story and that it changed their view of eating disorder patients and their families. This was the response I had hoped for. I desired openness for dialogue and change, but deep down I had been scared that they might react negatively. Would they believe my story? Would they look at me differently after knowing the personal and unpleasant details of my life? Would they toss the paper aside and forget it? Instead my preconceived fears were dispelled as we discussed eating disorders and the power of stories. Pryer (2011) states:

Stories act as a springboard for the study of the self and of others in context, enabling the researcher to seek patterns in the complexities of everyday experience that illuminate cultural and social structures, identify formation and lived experience of power and possibility. The reflexive qualities of memoir allow the researcher to incorporate personal, emotional, sensual, embodied responses to the data. (p. 15)

The discussions with my colleagues were a springboard for my current study to explore memoir as a way of understanding the importance of supporting patients and families of adolescents with eating disorders, and the benefits of a collaborative care approach.
Act II: The Participants’ Response to the Memoir

After reading the memoir, a rich discussion ensued through the online focus group. My colleagues, who were the study participants, recognized the difficulties families experience prior to bringing their adolescent to the hospital and noted the kinds of barriers they faced in caring for patients with eating disorders. As I analyzed their responses, I found several themes including the need for education, lack of agreement about best practices for eating disorders, the hierarchies of health-care professionals, and judgemental attitudes. I also noted that they frequently commented on their emotional response to caring for eating disorder patients. Finally, participants spoke of the value of memoir.

Specialized education, knowledge, and training were repeatedly mentioned by participants as central to improving their nursing practices and caring for patients with eating disorders. Several remarked that nurses receive little education on eating disorders and other psychiatric disorders. Participants described a desire to provide quality care and their inability to do so, and noted that their lack of knowledge contributed to their frustrations and emotional reactions to and judgements of these patients. They noted that the lack of specialized education, ineffective care plans, and lack of resources meant that health-care professionals actually did more harm than good to patients and families. Updated polices, information, and support were outlined as ways to assist them in providing better nursing care.

Previous literature had shown similar findings. In a study by Thompson-Brenner et al. (2012), health-care professionals across disciplines reacted strongly to patients with eating disorders due to a lack of knowledge; they reported frustration, lack of
competence, and worry. Other studies (Atkin, Holmes, & Martin, 2005; Reed & Fitzgerald, 2005; Sharrock & Happell, 2006, as cited in Gerrety, 2012) also revealed that nurses lack confidence, knowledge, and/or skills when caring for clients with a mental illness, and that they desire more education and support in order to improve care and attitudes towards patients.

On the value of memoir, the participants claimed that it enabled them to become aware of their judgemental attitudes and emotions such as frustration, anger, sadness, and fear, and how these reactions affect the care they provide to families of patients with an eating disorder. They indicated resolve to increase their compassion and understanding in their nursing care. The memoir helped them to recognize that families often have been in turmoil long before their children were admitted to the hospital and are in need of support themselves. This was also identified in a previous study by Whitney et al. (2005) where several families, mostly mothers, demonstrated overwhelming emotion:

I was very emotional and couldn’t talk to anyone without crying and I could not sleep very well. And often cried myself to sleep as I could see what was happening to [her] and just felt helpless. (p. 447)

In the current study, it was apparent that participants learned, through memoir, the need to develop a deeper understanding of the struggles facing families and individuals dealing with eating disorders, including feelings of guilt, fear, and exhaustion.

Act III: The Educative Value of Memoirs

As described in Chapter 1, I hoped that this research would lead to changes in health-care professional practice, specifically to not only include and inform families
about the care of their adolescent, but also support rather than blame and judge them for the disorder. Reading the memoir helped the participants think about the person experiencing the eating disorder rather than just the disorder itself. Participants also spoke about how stories can interrupt the process of medicalizing patients and help nurses to personalize care. The memoir created an opportunity to discuss the importance of a more compassionate, empathetic, and partnership approach in caring for families and patients with eating disorders than is practiced now in order to support healing. The consensus was that if they do not understand what the illness or diagnosis means for each patient, they as nurses are unable to provide care that is meaningful for the patient.

In general, participants remarked that reading personal stories like this was powerful and could contribute to understanding the lived experiences of those for whom they care. The literature supports the notion that memoir as narrative can contribute to a collaborative approach in health care. Holloway and Freshwater (2007) identified that memoir helps health-care professionals gain a greater understanding of their patients, which contributes to more effective care and treatment. In one study, Karnieli-Miller, Vu, Holtman, Clyman, and Insu (2010) examined the use of narratives with 135 third-year medical students within the clinical environment. The medical students recorded stories that taught them something about professionalism and professional values. One student relayed a story about one of her patients:

Apparently, nobody had ever discussed with the patient why they were having certain symptoms, what her diagnosis might be, and what her medications and tests were for. She stated that she sat down with the patient for 30 minutes and
explained everything to her. Not only does the patient deserve this, but it will help with medication compliance and decrease readmissions. This medical student recognized this and showed initiative and responsibility by taking this time for the patient. (p. 129)

The outcome of the study strongly suggested that narratives were a rich source of information that facilitated dialogue, training, and faculty development. Further, Gaydos (2005) explored the need for personal narratives and their relevance to nursing practice. She asserted that “working with people to uncover deep meanings in their stories creates opportunities for healing and for hope as old self stories are rewritten and new ones are envisioned” (p. 254). Personal narratives in nursing practice, according to Gaydos, not only offer insight into a patient’s history, but also create and maintain a relationship in the present. She concluded that the “interactions of a listening nurse with a narrating patient is critical to revealing meaning in the self-story and to creating new meanings that are necessary to re-envision the self-story” (p. 256). Personal narratives in nursing, especially in psychiatric mental health nursing, in which a patient’s self-story is often the source of much suffering, were considered important.

**Act IV: To Be Continued**

Since the completion of the study, I have had numerous discussions with my nursing colleagues about how their participation in this study has affected them. Whenever I am working in the pediatric unit, colleagues approach me to say that they are so glad they took part in the study and that they now view families of patients with eating disorders differently. I have received many positive comments such as “I feel more confident and actually take the time to get to know the mother and ask how she is...
doing . . . I listen to her story.” Another colleague shared that after hearing a mother’s story she “spontaneously hugged her and immediately saw a change in the mother’s face . . . like someone cared about her.” It was so encouraging to hear these and other positive comments.

Of significance, nursing colleagues that did not take part in the study have also shown interest and have been asking questions. I was elated to hear my colleagues explaining the study to the other nurses and how the process changed them. It was a wonderful opportunity for them to share the findings and the power of stories.

After the study, the patient care coordinator of the pediatric unit, who took part in the study, recognized the need for more education and was able to secure funding for a part-time mental health nurse to be available as a resource on the pediatric unit. This nurse provides workshops, in-service, and one-on-one consultation to the nurses in our unit to discuss ways to have meaningful conversations with families and patients with mental illnesses and eating disorders. As well, the funding was used to buy copies of my book, A Melody of Hope: Surviving Your Daughter’s Eating Disorder (2011), which is comprised of true, inspirational stories written by mothers who have daughters with an eating disorder. Each parent is loaned a copy of the book when an adolescent is admitted to the pediatric unit. It is our collective hope that these stories will provide support and encouragement.

I am humbled by the response and changes in our pediatric unit. The nurses in our unit had always regarded themselves as kind and caring, but became anxious, frustrated, and judgemental when not provided with the necessary education and training while caring for families and patients with eating disorders. This was identified
in the online discussions of the study. I believe this study came at a pivotal time as the nurses in my pediatric unit were ready and seeking change. The study facilitated a rich discussion with suggestions for moving forward. Memoir has been shown in both the literature and this study to be a powerful and rich source of information that facilitates critical reflexivity in nurses, enabling them to comment on their practice and areas that need strengthening. The memoir and online focus group also facilitated a dialogue that continues to uncover deep meanings and create opportunities for healing and hope.

The next and concluding chapter presents a summary of the research process and findings, addresses the gaps in knowledge, and provides implications for nursing practice, education, and research. I will also offer my closing reflections.
CHAPTER SEVEN: SUMMARY, IMPLICATIONS AND REFLECTIONS

In this concluding chapter I return to the beginning and reflect on my motivation for conducting this research. I then summarize the research process and findings, discuss to how the study addresses gaps in knowledge, and outline some implications for nursing practice, education, and research. I brought to this inquiry multiple roles including as a mother of a daughter who suffered with an eating disorder, as a Registered Nurse employed on a pediatric hospital unit, as a nursing instructor at UBC Okanagan, and as an EdD student undertaking critical investigation of my own practice. I conclude with reflections on how this study impacted those various social locations.

**Motivation for this Research**

This research study began after my daughter recovered from an eating disorder and I wrote about my experience as a way to make sense of what happened. After writing my story I was amazed at the peace I had. I recognized that my lack of understanding of the disorder, my preconceived notions of the cause, and my role as a pediatric nurse were factors in my feelings of guilt and shame. A few of my nursing colleagues read my story and revealed how it changed their view of the patients and their families. My colleagues also shared that they were determined to be more understanding and caring. They realized that everyone has a story and needs compassion. This response was the motivation for this research study.

To fulfill the requirement of the EdD program, I implemented a critical investigation of my own nursing practice by conducting a study with my colleagues to explore the negative impacts on families when health-care professionals blame and judge families. The goal of the study was to contribute to the existing body of
knowledge about the impact of eating disorders on families and how collaborative and supportive care for patients with eating disorders and their families can improve recovery.

**Summary of the Research Process and Findings**

My main research question was: What contributions arise from writing a memoir about the impact on a family of a female adolescent with an eating disorder and the family’s encounters with health-care professionals? My sub-questions were: a) What is the outcome of sharing that memoir with health-care professionals? and b) How can this memoir contribute to a collaborative approach to treating eating disorders that respects and includes the family?

To answer these questions, I designed a two part study. Part one was comprised of the qualitative research method called ‘memoir.’ I revised my original memoir to include my journey through my daughter’s experience with an eating disorder from my perspective as a mother, my interactions with health-care professionals, and my role as a health-care professional caring for adolescents with eating disorders. Part two involved an online focus group. A group of health-care professionals were to read my memoir and respond to predetermined open-ended questions.

The main goal of the study was to explore what could be learned from the writing of a memoir about the impacts experienced by families when a female adolescent has an eating disorder. After reading the memoir, a rich discussion ensued with participants recognizing the difficulty families experience prior to bringing their adolescent to the hospital. The participants talked about how reading the memoir brought a self-awareness of their personal judgemental attitudes and emotions such as frustration,
anger, sadness, and fear, which affect the care they provide to these families. The participants acknowledged that their judgemental attitudes and emotions affect the care they provide to these families and patients, and it was this knowledge that brought about a resolve to be more compassionate and understanding in their nursing care.

In this study, I also explored what a memoir could contribute to the current knowledge and practices of health-care professionals related to treating patients with eating disorders. After reading the memoir, participants recognized the contribution that specialized education, knowledge, and training could have. Several participants remarked that nurses do not get enough education on eating disorders and other psychiatric disorders. The memoir was also instrumental in aiding the participants in linking their feelings of frustration and anger with the outdated care plans and inconsistent approaches utilized in the pediatric unit. The participants identified resources such as updated polices, information, and support as a way to assist them in providing better nursing care.

Finally, I considered the value of memoir as an educational resource and how memoir could contribute to a collaborative approach to treating eating disorders that respects and includes the family. Participants in the study indicated that memoirs are valuable to health-care professionals as they make them think about the person experiencing the eating disorder rather than just the disorder itself, and this holistic, compassionate, and empathetic approach can facilitate the lessening of judgmental attitudes and increased collaboration with families.
Addressing the Gaps in Knowledge

Previous research studies reflected my own experiences, outlined in my memoir, that families experience anxiety, depression, stress, and burnout while caring for an adolescent with an eating disorder. The literature also revealed that families placed importance on being acknowledged by health-care professionals as an integral part of and resource for their adolescent’s recovery and treatment process. The results of this current research study aligned with previous studies that reveal that health-care professionals lack the education and understanding necessary for providing care and treatment to patients with eating disorders, leading to frustration, burnout, trust issues, and engagement in power struggles with patients with eating disorders, thus negatively impacting patient care.

This study adds to the existing body of research, which has explored the negative impact of both eating disorders as well as health-care professionals’ lack of knowledge and judgmental attitudes on families. This study also adds to existing research on the value of narrative and memoir as an educative process. What needs to happen now is putting this research into practice.

Implications for Nursing Practice

The findings of this study point to how nurses are hungry for better knowledge and greater confidence in caring for families and patients with eating disorders. It is clear that more specialized education, training, and resources are needed (more on this topic follows in the next section). Eating disorders are a mental health issue and much more education about this wide area of practice must be included in foundational as well as continuing professional education of nurses. Hospitals and clinics working with
patients and families with eating disorders would greatly benefit from hiring mental health nurses who can support the nurses as well as the families and patients with mental health issues including eating disorders. The mental health nurse would be a valuable source of knowledge, and can provide information and offer possible solutions to specific situations or issues that arise relating to mental illness. Ongoing educational workshops and in-services for nurses (as well as patients and families) should be offered.

This study and previous research point to how nurses experience frustration, anger, and sadness while providing care for this patient population. Patient care coordinators (PCC) of pediatric hospital units could schedule regular staff meetings to talk, share, and debrief. The usefulness of online debriefing and discussion groups should be explored. This could also be another place for the mental health nurse to participate and share coping methods other mental health nurses use while caring for families and patients with mental illness.

The hierarchy between doctors and nurses also emerged from this study as a barrier to effective care. An inter-professional team approach where all health-care professionals involved with care of patients with eating disorders and their families would be helpful.

**Implications for Education**

It was evident from the literature and current study that health-care professionals feel educationally unprepared to care for patients with eating disorders. It would be prudent, therefore, to begin the education in nursing school. As noted, opportunities for specialized education should be developed and the approach could be inter-
professional. Adjunct lecturers or guest speakers with expertise in mental health and eating disorders could be retained to provide education and a better understanding of the disorder.

Memoirs are a valuable educational resource that can enable a more holistic and empathetic approach. Stories and memoirs could be employed to a much greater extent in health-care professionals’ education; they help to build relationships and encourage critical reflexivity in the reader. Holloway and Freshwater (2007) affirm that narratives help health-care professionals gain a greater understanding of their patients, which contributes to more effective care and treatment.

**Implications for Research**

I recommend conducting further research at eating disorder centres and pediatric units to explore how specialized education and training of health-care professionals influence judgemental attitudes and if it improves care and recovery rates for adolescents with eating disorders. It would also be interesting to explore what kind of education and training as well as provision of resources such as up-to-date care plans contributes to nurses working collaboratively with families.

Given the impact of the memoir outlined in this study, it would be prudent to conduct further study on the role of memoir as an educational resource in schools of nursing. Researchers could consider how memoir affects students preparing to work as graduate nurses. Similarly, further study of the role of memoir as an educational resource in other disciplines such as medicine, psychiatry, social work, and education would also be beneficial. Research in these areas could consider the benefits of memoir and how it can be applied.
More research into the value of internet and online forums would reveal other ways to maximize its potential to create communities of practice. How online learning spaces allow for anonymity and greater disclosure of personal experiences, emotions and reflections is worth further inquiry. This anonymous but personal method helped the health-care professionals from the same pediatric unit share their responses with honesty and critically reflect on their own practice. It would be interesting to carry out further research that compares diverse kinds of forums including online and face to face.

It would also be useful to further explore how memoir can assist mothers of daughters with eating disorders to narrate their struggles as a process of self-discovery and journey towards a new understanding and healing.

A follow-up to this study could involve exploring how the discussions and newly implemented changes (discussed in Chapter 6) in the pediatric hospital unit at which I am employed have fostered collaborative and supportive care for families of adolescents with eating disorders and if these changes have improved recovery rates.

Closing Reflections

Conducting this study has impacted me as a mother, a health-care professional, a faculty member in a nursing education program, and doctor of education student. As a mother of a daughter who has suffered with an eating disorder, I have more empathy and understanding for families caring for a daughter with an eating disorder. As a health-care professional employed on a pediatric unit, this study has deepened my commitment to working in partnership with families and individuals with eating disorders. I now encourage families to share their story, and I offer words of hope,
encouragement, and support. As a nursing instructor, I am aware of the need for more education, and am seeking ways to implement memoir and story into the curriculum as an educational resource. And finally, from this study I have developed confidence as a practitioner scholar and hope to engage in more practiced-based inquiry. I have more compassion for my colleagues who struggle to provide high quality care. I have also deepened my resolve to slow down and listen to their stories and to the stories of my colleagues. I encourage other researchers to consider memoir as an approach to exploring problems in their arenas of practice and to consider stories as a methodological and pedagogical resource.
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http://www.caringonline.com/feelings/byvictims/


http://dx.doi.org/10.4236/ojn.2012.24059


Registered Nurses needed for a UBC Study exploring how memoir can contribute to a more collaborative approach to treating anorexia that respects and includes the family

- Have you ever wondered why you struggle with providing care for children with eating disorders?
- Have you thought about other family members caring for children with eating disorders?
- Have you considered how others’ experiences with eating disorders could impact your own practice?

If you have wondered about any of these questions, are you interested in being part of a study that explores these questions and others like them?

Why not join a confidential online group to discuss this and learn from each other.

The estimated time of involvement for this study is 3-5 hours depending on your contribution. The study is expected to start December 2, 2013 and finish on January 2, 2014.

This research is being conducted as part of my graduate dissertation. To sign up or if you want to learn more about this study, please, contact Cathy Robinson at: xxxxxxxxxxxxxxxxx. Deadline for reply is November 28, 2013.
Appendix B: Consent Form

Consent Form

Can Memoir Contribute to a More Collaborative Approach to Treating Anorexia that Respects and Includes the Family?

I. STUDY TEAM

Principal Investigator:
Dr. Carl Leggo, Department of Language and Literacy Education, University of British Columbia-Vancouver. Email:xxxxxxxxxxxx (xxx)-xxx-xxxx.

Co-Investigator(s):
Cathy Robinson, Graduate Student, Doctor of Education Program, University of British Columbia-Vancouver. Email xxxxxxxxxxxxxxx (xxx)-xxx-xxxx.

Dr. Shauna Butterwick, Department of Educational Studies, University of British Columbia-Vancouver. Email: xxxxxxxxxxxxxxx (xxx)-xxx-xxxx.

Dr. Barbara Pesut, School of Nursing, University of British Columbia-Okanagan. Email: xxxxxxxxxxxxxxx (xxx)-xxx-xxxx.

II. INVITATION AND STUDY PURPOSE

You are being invited to take part in this graduate dissertation study. The purpose of this study is to provide a first person account, in the form of a memoir, of the negative impacts experienced by patients and families when nurses judge and blame families, and particularly mothers, for the patient’s eating disorder. This study also focuses on how memoirs can be a source of information for nurses and other health care
professionals. We are doing this study to explore how memoir can contribute to a more collaborative approach to treating anorexia that respects and includes the family.

III. STUDY PROCEDURES

You are being asked to voluntarily participate in this study because you are a registered nurse with at least 1 year post registration experience and working on the pediatric unit and caring for families and patients with eating disorders. It is anticipated that there will be 6-10 participants. Within this study, you will be asked to read a memoir about the experience of a mother of a daughter suffering with an eating disorder as well as her experience as a nurse caring for adolescent patients with eating disorders. You will then participate in an online focus group answering and discussing 4 posted questions. You will have access to this online discussion group for a period of 2 weeks. During this time you will be asked to respond to the questions and the subsequent discussions posted by other participants. Given the nature of the discussion, you will be asked to use particular etiquette to facilitate involvement. The total time commitment of your participation will be 3-5 hours depending on your contribution.

IV. STUDY RESULTS

The discussion posts will be reviewed and analyzed thematically to explore the value of memoirs as sources of information for nurses and other health care professionals, and whether memoirs can contribute to a more collaborative approach to treating anorexia that respects and includes the family. The results of this study will be reported in a graduate dissertation and may also be published in journal articles and books. At the completion of the study, you will have access to the dissertation upon request. The dissertation is considered a public document and will be available on the internet.

V. POTENTIAL RISKS OF THE STUDY

A potential risk associated with the study is a perceived conflict of interest in that Cathy Robinson is both the co-investigator and work colleague. To reduce this risk you will be assigned a non-identifiable code number by the Centre for Teaching and Learning at UBC Okanagan when participating in the on-line focus group discussions.

We do not think there is anything in this study that could harm you or be bad for you; however, some of the questions we ask might upset you. If at any time you have any concerns, please contact the co-investigator, Cathy Robinson. A list of psychological or emotional professional supports will be available upon request or if needed. As a token of appreciation for participating in the study, each participant will receive a $5 Tim Horton’s gift card.
VI. POTENTIAL BENEFITS

A potential benefit of participating in this research is a better understanding of how experiences with health care professionals affect families and ultimately impact the recovery of adolescents with eating disorders.

VII. CONFIDENTIALITY

Your confidentiality will be respected. Information that discloses your identity will not be released without your consent unless required by law. All documents will be identified only by code number and kept in a locked filing cabinet in Cathy Robinson's office at UBC Okanagan, and computer files will be password protected. Only research staff associated with this project will have access to the data. All paper data will be stored for at least 5 years after publication of the study. 5 years after publication paper copies will be shredded.

You will not be identified in any reports of this research. Information from this study may be used again for further research to improve practice for patients and families. Information collected in this study may also be used for teaching purposes without revealing any information that identifies you.

This study is for a graduate degree and information from this study is part of a dissertation (public document).

VIII. CONTACT FOR INFORMATION ABOUT THE STUDY

If you have any questions or desire further information, you can contact Dr. Carl Leggo or anyone on the research team. The names and telephone numbers are listed at the top of the first page of this form.

IX. CONTACT FOR COMPLAINTS

If you have any complaints about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at x-xxx-xxx-xxxx or the UBC Okanagan Research Services Office at xxx-xxx-xxxx.

You may also contact the Chair, Interior Health Research Ethics Board by phone at xxx-xxx-xxxx or by email to xxxxxxxxxxxxxxx.

The Interior Health Research Ethics Board carried out an ethics review for this research project and made a determination that it met ethical requirements for research involving human subjects."
X. PARTICIPANT CONSENT AND SIGNATURE PAGE

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason. If you withdraw the data you have contributed thus far will remain part of the study.

- Your signature indicates that you consent to participate in this study.
- Your signature below indicates that you have received a copy of this consent form for your own records.

____________________________________  __________________________
Participant's Signature                Date

____________________________________
Printed Name of the above
Appendix C: Letter of Etiquette

UBC Study

Can Memoir Contribute to a More Collaborative Approach to Treating Anorexia

that Respects and Includes the Family?

Etiquette to Facilitate Online Involvement

➢ Post anytime.

➢ Avoid using your name.

➢ Avoid using patient names or any identifiable situations.

➢ Respectful criticism is encouraged.

➢ Do not post any defamatory, abusive, profane, threatening, or offensive messages.

➢ All posts are to be considered as confidential and, as such, postings are not to be discussed with others.
Appendix D: Resources for Participants

UBC Study:

Resources for Participants

Interlock- The Employee and Family Assistance Program (EFAP).
Employees of Interior Health may contact Interlock by calling
1-800-663-9099

Mental Health Hotline
1-866-531-2600

HealthLinkBC
Non-Emergency Health Information-811