Lost Alongside My Daughter with Anorexia Nervosa A Mother's Story

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Abstract— **We used narrative principles to represent the story of a mother caring for her adolescent daughter hospitalized with anorexia nervosa. The data were greeting cards, daily letters written by the mother to her daughter, and audio-taped individual interviews with the mother and daughter. We identified themes or categories of information (e.g., settings, relationships, temporality, and voice elements) within the mother's story, and re-storied them into a chronological plot incorporating the mother's struggle and its resolution. Narrative threads of seeking a clearing, drawing strength, taking stock, ethic of repair, fending off the beast of starvation, and homecoming were identified. Together these threads comprise the core story of "*lost alongside my daughter*" that describes the mother's overarching concern for the daughter's immediate and future well-being while seeking a pathway to contribute to her daughter's care in a meaningful way.**

Keywords- eating disorder; narrative research; mother-daughter relationship

I. INTRODUCTION

In this article, we represent the story of a Canadian mother caring for her adolescent daughter with anorexia nervosa (AN), an eating disorder characterized by self-starvation and excessive exercise. Using narrative principles, we convey the mother's account of her experiences and struggle to support her daughter's recovery within larger health service delivery and socio-political systems. The data were cards and letters given to the daughter by the mother and individual interviews with the daughter and mother. We describe the care situation, the data, and our rationale for using a narrative approach. We present our findings as a composite letter conveying the mother's core story of feeling lost alongside her daughter. Our interpretation of this core story with discussion of its individual narrative threads of seeking a clearing, drawing strength, taking stock, ethic of repair, fending off the beast of starvation, and homecoming follows. The findings portray the mother as learning to effectively care for her daughter living with an eating disorder and the significance of providing this kind of care. Moreover, these findings illustrate the benefits and rigor of narrative methodology in research and practice with vulnerable persons in care.

II. BACKGROUND LITERATURE REVIEW

Eating disorders affect approximately 0.5% of Canadians aged 15 years and over[1], up to 30 million people of all ages and genders in the U.S. [2], and 70 million individuals worldwide[3]. Eating disorders have the highest mortality rate of any mental illness, with reported rates as high as 10-20%[4,5] and multiple co-morbid issues including depression, anxiety disorder, bipolar disorder, post-traumatic stress disorder, substance abuse, self-harm, and obsessive compulsive disorder[6,7,8]. Health complications can include organ failure, cardiac arrhythmias, infection, malnutrition, substance misuse, and suicide[9, 10, 11]. For eating disorder clients who have a history of suicide attempts, the risk of death from any cause is 12.8%, with suicide being the main cause in 45% of those deaths[12].

The compounding mental and physical health issues related to eating disorders make it imperative to focus intensive effort on recovery. However, families are challenged to best help their child with an eating disorder while not always being able in Canada to access comprehensive services[1]. The services that are available may be perceived as stigmatizing, particularly toward mothers [13]; the eating disorders culture has been labelled "mother blaming"[14](p.70). This dates back to the Industrial Revolution, a time when mothers were considered the prime cause of positive or negative development in their children, being held responsible and even blamed for the type of person a child turns out to be[15]. Even in the 1970s, interviews conducted by Minuchin, Rosman, and Baker [16] contained statements made to mothers such as "You are attacking your husband and killing your daughter" (p. 165). Newer findings have continued to convey mothers as "over involved and enmeshed" [17] (p. 136). More recently, eating disorder development has been associated with maternal body dissatisfaction [18] as well as mothers' hostility, drive for thinness, perfectionism, and ineffective awareness of self and body [19]. Although some research findings also associate paternal characteristics with eating disorder development [19], most samples include more mothers than fathers. Given the stress of caring for a child with an eating disorder and the insidious downward spiraling from functional child to pathological state, and the historical mother-bashing noted in the literature, it is understandable that when a child is diagnosed with such a serious illness as an eating disorder, the mother may feel guilty that she actively did, or failed to do, something that resulted in the development of her child's eating disorder; and unprepared or inadequate to help with the child's recovery. Deeper understanding of the mother's experiences of caring for a child with an eating disorder will update health science and inform care intervention.

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III. MOTHER'S STORY

This story began with the daughter's second hospital admission. The daughter, a 15 year old grade 10 student, had been diagnosed with AN shortly after entering high school, hospitalized for 4 months, discharged after making a minimal weight gain of 4.5 kilograms (10 pounds), and re-hospitalized within two months. At 175 cm (5'9") and 39 kilograms (86 pounds), the daughter did not agree she looked emaciated. However, her mother, a 44 year old history teacher and the primary care giver in the family, was overwhelmed by the extent of her daughter's condition and the need to help her daughter while not knowing how to best accomplish this. In addition to the mother and hospitalized daughter, the family included the husband (part-time accountant) and two older daughters aged 17 and 19 years living at home while attending high school and university.

> *I was afraid she [youngest child] would die . . . like she was on death's door. She was continually exercising. It seemed as if she would never get out of the hospital, and that she had a death wish. At times I walked softly in the health-care system because of this. I sometimes felt helpless in regards to her health-care.* (Interview with Mother [MI])

To *"do something"* to communicate her love and support for her daughter, the mother began to write daily to her daughter in letters and cards. The mother's story is one of striving to overcome the confusion and bewilderment of finding herself beside a seemingly mystical creature called AN that bore little resemblance to the daughter she once embraced and committed to her nurturing.

IV. NARRATIVE APPROACH

We chose a narrative approach to analyze the messages in the cards and letters because this allowed us to uncover possible meanings the mother was making from her experiences of caring for her daughter with AN and to explore the interplay between the mother's personal experiences and larger social processes. A narrative approach enables discernment of underlying structure and issues related to power, domination, and opposition, giving voice to silenced individuals through their stories [20]. Such stories are logical and temporal in that they contain sequences of events with beginnings, middles, and ends [21]. Narrative analysis yields descriptive findings that clarify the significance of events based on the resultant outcome [22] and organize experiences to tell and retell key information to others [23].

A. Researcher Worldview

Our analytic approach was located within the interpretive research paradigm, a view supporting co-construction and coexistence of multiple truths and realities. Research via this paradigm provides opportunity for the voices, concerns and practices of research participants to be perceived and enables understanding of the whole phenomenon through the perspectives of those who live it [24, 25]. Our research focus was, as Cole [24] argues, "more concerned about uncovering knowledge about how people feel and think in the circumstances in which they find themselves, than making judgements about whether those thoughts and feelings are valid" (p. 26). The type of understanding sought demanded flexibility as there are different ways to think qualitatively about the data, analytic process, and use of creative approaches [26]. It is widely recognized that qualitative researchers serve as the research instrument, relying on their own skills to receive information in natural contexts and uncover its meaning by descriptive, exploratory, or explanatory procedures. Aware that qualitative research has at times been regarded as "contested work in progress" [27] (p. 15) because alternative explanations for findings can be developed, we maintained rigor through careful reading and rereading of the data, ongoing face-to-face research team meetings, openness to multiple possibilities or ways to think about the data, and returning emergent threads and themes to participants for corroboration. Our production of a logical chain of reasoning using multiple sources of converging evidence to support the findings contributed to good science.

B. Characteristics of the Data

The mother's story was inimitably conveyed in an extensive set of cards and letters (Table 1) that she wrote to her daughter every day the daughter was hospitalized. The mother chose the medium of the cards as "a way for her [daughter] to hear me, ... an emotional connection" because the daughter, having been hospitalized involuntarily, was verbally "attacking" the mother and "refused to listen" during hospital visits. The mother visited her daughter once or twice a day but the cards and the letters were the main way the mother maintained the relationship. This situation was unique because mother and daughter acknowledged they did not do well verbally as evidenced in the following excerpt in one of the letters:

> *Thank you for the letter you gave me last night. I agree with you. It is so much easier to communicate in pen and paper than by word. I think this is mainly because you take time to consider what you are going to write, but when you say something, often you think about it after you have said it and realize that it was the wrong thing to say. Unfortunately, you cannot crumble up what you have said or scratch it out. There are so many times in my life when I have said something to you, your sisters, your Dad and some of my students that I wish I could have been able to rewind and erase what I have said. Life is like that, though. Often we don't think about what we say because we are afraid of the empty quiet minutes we take to think before we say something. I guess this is one of my worst habits … The urgency to say something has always gotten in my way in producing healthy instructive comments. This is something I have to work on!* (Letter from Mother [LM] 2)

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TABLE 1. CARDS AND LETTERS TO DAUGHTER

Item	Cards and letters		
	Number	*Description*	*Signature*
Cards with commercially prepared messages [CM]	68	Cards containing commercially prepared messages with handwritten signatures only	Love Mom & Dad XXXOOO
Cards with commercially prepared & handwritten messages [CMHM]	19	Cards containing commercially prepared messages and brief handwritten messages	Love Mom & Dad XXXOOO (14), Love Mom XXXOOO (5)
Cards with only handwritten messages [CHM]	36	Cards containing full page handwritten messages.	Love Mom XXXOOO
Letters from Mom [LM]	46	Handwritten letters 1-3 pages in length.	Love Mom XXXOOO
Cards from Dad	2	Penciled figures (e.g., happy face) hand drawn on folded white paper	LOVE Dad

The set of cards and letters were not specifically generated as artifacts from research processes, but were privately written communications from the mother to her hospitalized daughter. The cards and letters were freely offered to the first author by the mother with the permission of the daughter. Both mother and daughter wanted to make their experiences, learning, and practical strategies available to health professionals and other families. Ethical approval for the study was then sought and granted from the authors' academic health research ethics board; written informed consent and on-going verbal consent were obtained for the interviews. We have replaced all personal names with descriptors of Mother, Daughter, Father, and Sister.

C. Process of Analysis

The cards and letters were catalogued; handwritten and commercial messages were transcribed with names and other identifying information removed. The letters written by the mother and interviews with the daughter and mother were transcribed and anonymized. Drawing on principles for narrative analysis as outlined by Emden [28] and Polkinghorne [29], we sorted the data chronologically, identifying elements that illuminated the mother's experience of learning to support her daughter and constructing a single comprehensive core narrative from the many messages in the cards and letters. We analyzed the messages to determine how the mother understood the meanings of health and illness in her daughter's life, gave shape to the events she described, and communicated to her daughter. We examined the images and commercial content of the cards, and analyzed the mother's handwritten letters by asking ourselves, as Cortazzi [30] suggests, What is this about? Who are involved? What happened? Why? When and where did it happen? What happened next? What could it mean?

Moving back and forth using a process Polkinghorn [29] refers to as tacking, we compared subplots within the events portrayed in the card and letter messages and revised the emerging core narrative via the principle of best fit (identifying and matching characteristics of one entity with those of another to determine the presence of similar characteristics that enabled data to be linked and the level of abstraction raised [31]). This allowed a dialectic process to occur between the events themselves and the narrative thread which disclosed their significance and allowed them to be grasped together as parts of one story [29]. The resultant core story encompassed key aspects of the mother's story of being lost alongside her daughter with an eating disorder, synthesizing the data into an interpretation of which we as researchers, the mother and daughter as research participants, and future audiences could make theoretical sense.

Collaborating with our participants, we shared ideas about the narrative threads we found in the data and we maintained contact with the mother and daughter individually via telephone and email communications. The first author conducted telephone interviews with the daughter and mother who verified our findings in the form of successive drafts of this article. Our coming to understand the mother's story was facilitated by inductively bringing into the analysis relevant selections from classic and feminist literature including Dante's allegorical journey described in *Inferno, Volume One of The Divine Comedy* [32] and Maureen Murdock's *The Heroine's Journey: Woman's Quest for Wholeness* [32]. This literature was not imposed on the data, but rather, added as the data "spoke for themselves" and conceptual categories and descriptive themes **developed.** Such approach helped us understand, contextualize, and convey the grip and terror of the mother's struggle. It further allowed a perspective that the mother supported in her final feedback. *"This [core story] shows what actually happened to me. I see my ordeal more clearly and deeply, and how I strove to help her [daughter]. Thank you for telling my story this way."*[MI]

V. FINDINGS

The mother-daughter relationship was embodied in the written correspondence and our understanding of the relationship is based on this written correspondence. The mother used cards with and without commercially prepared messages to communicate with her daughter throughout the daughter's three month hospitalization. The cards provided an immediate impact by the nature of their pictures. Often, the mother relied on the commercial messages contained in the cards. Other times, she referred to the cards to help point out to her daughter the daughter's abilities; for example, the mother positively compared the daughter's painting style with that of van Gogh. Less often, the mother personalized the commercial messages of the cards with brief

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handwritten messages. Together the cards and letters illustrated the complexity of the mother's communication by picture, commercial poem, and handwritten text.

A. Messages of the Cards and Letters

- *Messages by Picture*

The story of the cards is based on our interpretation of different kinds of cards and messages: cards with commercially-prepared messages, cards with commercially-prepared messages and handwritten messages, and cards with only hand-written messages. The cards communicated a message even when the mother was unsure if the daughter would read the letters. Thus, whether or not the daughter opened up the cards or read the letters, the pictures on the cards and the intended impact of the pictures on the daughter were important. All the cards were in the mother's handwriting except for two pieces specifically hand designed and signed *LOVE Dad* and with a happy face icon drawn on front of the paper. We did not include the father's cards because the messages were short and straightforward (e.g., "I love you honey bear. It's good to have you home" and "I promise to get SISTER'S room finished. I will see you tonight").

- *Messages by Cards with Commercially-Prepared Messages [CM]*.

All the cards signed "*Love, Mom and Dad XXX000*" are in the mother's handwriting. The art on the majority of these cards reflects nature, plants, animals, rainbows, and scenic views. Relatively few are comical (e.g., "hanging in there", cartoon figures). One card instructs to wrap the card around self and squeeze for a hug. The cards convey an overall feeling of love and worry; the receiver of the card (the daughter) is meant to know that the senders (Mom and Dad) have faith in her and that she will survive the current situation. According to the messages of the cards, this survival journey would be long and tough, and perhaps only God knows how difficult it is, or why it is happening; yet, everyone's love, support, prayers, and active thinking will help in this journey. The verses and poems are powerful. The cards were the mother's way of trying to be present all the time for her daughter. They could take the place of the actual person because the daughter could keep them and look at them any time.

- *Messages by Cards with Commercially-Prepared and Handwritten Messages (CMHM)*

The cards signed *"Love Mom XXXOOO"* contain short messages (e.g., *"Thank you for the gift"*, *"Sorry you did not have a good pass").* Of the cards signed *"Love Mom & Dad XXXOOO,"* one card with glitter over it shows a Victorian-style child angel with the message: "*This card reminds me of you, when you were a little girl. You were such a sweet, little angel, so loving and innocent!*" (CMHD 12). The messages express a thought at the moment and do not replace time spent away. For example, *"Dear Daughter, I hope your day was a good one and that you sleep well tonight!"* (CMHD 13). The mother apologizes for "*lame cards*" (CMHD 7, 8, 9) that do not adequately convey what she herself cannot say.

- *Cards with only hand written messages (CHM)*

The selection of cards is important as the mother uses the impressionist pictures on the front of some of these cards to catch her daughter's attention *"The picture of water lilies is very calming and peaceful, and this is the kind of card I really like. Do you think it was hard to paint this kind of picture?"* (CHM 5). The choice of cards without commercially prepared messages puts the onus on the mother to compose individualized messages as evidenced by her message: *"These cards are nice, but I feel obligated to write in them since there is no pleasant message inside"* (CHM 1). The cards are used by the mother to articulate her love, concern, and need for connection with her daughter but also her difficulty in articulating her feelings. The mother's handwritten messages are similar to, yet more personalized than, the messages in the commercial cards: Life is complicated (CHM 1); you are as special, unique, and complex as nature or flowers (CHM 4, 10); I love you and want you to get better so you can enjoy life as does your Dad and the rest of your family (CHM 2), and you have special abilities (e.g. painting) (CHM 5, 8, 18). As the hospitalization continued, the mother replaced the longer daily letters with shorter messages in these cards.

- *Letters from Mother (LM)*

On the surface, the mother's letters contain stories about her teaching and job-related extracurricular activities, family care-giving, and advice for managing the eating disorder and various developmental and situational life events. As with the cards, there is an overarching theme of concern for the daughter's immediate and future well-being. The following narrative threads are identified in the letters and supported in the cards: lost alongside, seeking a clearing, drawing strength, taking stock, ethic of repair, fending off the beast (of AN), and homecoming. Several threads intermingle.

B. Lost alongside

The mother describes *"life [as] not the same around here without you"* (LM 8) and hence her initial and recurring lament of *"I miss you Daughter."* The mother is referring to losing her daughter to the AN as well as to the daughter being hospitalized. The mother is feeling frazzled and overextended from caring for her hospitalized daughter amid full-time teaching responsibilities and attending to other family members. As the daughter vents anger at the treatment program and its outcomes, the mother feels torn and confused by conflicting advice and the *"experimental"*-like quality of the treatment approach. She writes to her daughter, "*I know you must find things as confusing as your father and I do ... Frankly, I think they have not seen many cases like yours and they are learning as they go with your case"* (LM 27). Rather than feeling connected with and

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helped by those providing professional care, the mother is overwhelmed and is lost alongside her daughter. And while encouraging her daughter to speak up, she finds it difficult to have her own voice heard in the treatment decisions. The situation is urgent, complicated, prolonged, exhausting, and *"unreal"* (LM 30). The mother is filled with anxiety, unanswered questions, guilt, disconnection, fear, and inadequacy. She unabashedly hopes and prays for her daughter to recover and to cooperate with the treatment approach (LM 7; CHM 6). The mother's state resonates with Dante's description of "heart plunged in fear … where the sun is mute" [32] (Canto I, lines 15, 60). In the words of Dante, the mother has found herself lost in "a dark wood ... of wilderness, savage and stubborn, ... a bitter place!" (Canto I, lines 2,5,7).

The mother's experience also resembles Murdoch's [33] description of people striving to actively contribute in the world while fearing the cost of a progress-oriented society to the human psyche. The journey "has no well-defined guideposts nor recognizable tour guides ... no map, no navigational chart … It is a journey that seldom receives validation from the outside world; in fact the outer world often sabotages and interferes with it" (p. 3).

C. Seeking a clearing

The mother immediately addresses competing demands (e.g., work related grading and personal income tax reporting) to free up time to think about and be with her daughter. The mother's list of to-do things is extensive and exhausting to read in the letters. The mother wishes *"I could snap my fingers and it was all done"* understating that she will *"be glad when school is over and I can relax for a while"* (LM 19). The mother seeks the type of clearing described by Dante as a hilltop view "that leads [all people] straight ahead on every road" [32] (Canto I, line 18). Freeing herself from time sensitive demands helps position the mother in a clearing wherein she can more clearly apprehend the *"stranglehold your anorexia has on you[the daughter]"* (LM 31).

At the clearing, the mother stops doing so that she can simply be. Murdock describes such aspect of the heroine's journey as "listen[ing] carefully to her true inner voice, … silencing the other voices anxious to tell her what to do, … hold[ing] the tension until the new form emerges"[33] (p. 83). The mother wants to communicate her intent to be there for her daughter without *"boring [the daughter] to death"* or giving her *"too many things to worry about"* (LM 2). Yet, "being is not a luxury; it is a discipline" [33] (p. 83). Accordingly, the clearing is an emotional rather than physical territory maintained across the distance of the daughter's hospitalization. At the borders of the clearing is the mythical-like creature of AN. The mother strives to connect with her daughter amid the complex and contradictory aspects of the eating disorder and prescribed treatment regime. She tries to help her daughter interpret treatment team decisions to reduce panic on the daughter's part. For example,

> *Your health team meeting seemed to have gone quite well. It looks like they are willing to reward you in trying to follow their specific behavior directions. I don't think you should think this is because of any real weight gain. You have to realize that they are trying to reward behavior, not weight gain.* (LM 12)

D. Drawing strength

According to the mother, the daughter had *"negative, negative thoughts about herself."* The mother acknowledges the letter writing as an attempt to intersperse positive thoughts and support.

> *I couldn't really do anything with regard to looking after her health-wise because that's what the healthcare team was supposed to be doing ... The main reason I began writing to her was because ... I wanted to tell her I had confidence in her to overcome the anorexia. I tried to give her strength to make her feel better about herself* (MI).

The mother attempts to draw strength for her daughter to help the daughter maintain progress and help others regard the daughter in a positive light. In the letters, the mother details her own and other family members' activities to keep her daughter informed. The mother counsels her daughter regarding specific situations such as the unexpected death of one of her daughter's friends (CHM 23, 24, 25) and the need to *"be patient with your Dad"* (LM 21, 43). The mother liaises between her daughter and her daughter's teachers to facilitate the daughter's academic progress (LM 4, 10, 11, 13; CHM 8, 9), and between her daughter and the treatment team to facilitate recovery. For instance, she encourages the daughter to tell her ideas to the doctor [LM 31, 44]. The mother tries to enhance others' perceptions of her daughter by repeatedly pointing out her daughter's attractiveness, scholarship, athletic ability, and artistic talent (CHM 18, 33; LM 15, 18, 27, 29, 35). To illustrate,

> *This picture [front of card] is a yellow house by Van Gogh. It seems to have a great deal of detail. You could paint a picture as good [as] or better than this. This is my opinion, but you certainly have a lot of potential in art. You are also very pretty and have a lot of athletic skills that many girls your age don't have. Walking around the mall and seeing girls close to your age walking around with a baby or saying empty headed things to each other has always made me realize how glad I am to have such a bright girl like you for a daughter.* (CHM 18)

The mother attempts to keep the daughter's spirits up by offering nightly prayers, art supplies, daily visits, and interesting and enjoyable passes. She does not want her daughter to feel she must reciprocate, saying *"I don't expect you would write me every night as I do you"* (LM 2). The mother's letters tell what her heart is screaming: Daughter you are important, capable, worthy, loved, and integral to the mother's and other family member's lives. Drawing strength is fueled by love and commitment to her daughter.

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The mother draws strength despite feeling inadequate to help plan her daughter's care, and this is akin to Dante's lament that *"*no [one] would think me worthy" [33] (Canto II, line 33).

Drawing strength enables the mother to more effectively be there for her daughter. Murdoch [33] identifies a need to refine the "vessel" of self so that "the vessel can accept what is given to it, what comes through it" (p. 128). The process requires focused awareness and accepting oneself (i.e., not trying to prove oneself). The mother strengthens herself through replenishing (e.g., attending pleasant events such as a niece's wedding and dinner with her husband) and authenticating (e.g., disclosing her true feelings about doing things with the daughter she does not enjoy such as shopping at the mall [LM 45], expressing her own interests which include wanting to do a craft project she knows her daughter is not interested in [LM 38]), and unloading career disappointments [CHM 1, 2, 3, 10; LM 2, 4, 6. 9, 11, 19, 24, 25]).

E. *Taking stock*

The mother takes stock of her own and her daughter's situation by considering the immediacy of the hospitalization as well as the larger historical context. "The only things we really need to fear are those that have the power to do harm: Nothing else should cause us to be fearful" [32] (Canto II, 88-90). In taking stock, the mother appraises the effects of treatment on her daughter's well-being, identifying inconsistencies within the treatment approach. For example, she determines that team members "*at times seem so kind and loving and at other times ... like horrible mean people"* (LM 7). *"I realize that your nurses have to be firm with you, but I think it* [the behaviour of one particular nurse assigned to the daughter] *seems to be taken a bit too far. . ."* (CHM 15).

The mother appraises her daughter as an *"individualist… trying to discover who you are and what you stand for"* (CHM 33) while determining behaviours on the daughter's part that contravene recovery such as continuing to limit the amount of food ingested (see Figure 1).

The mother takes stock of any contribution on her part to her daughter's illness. According to Murdoch [33], modern-day heroines shape their futures by confronting their fear about personal power and ability to change social structures. "We can't go through life blindly. We have to examine all of the conflicting parts of ourselves" [33] (p. 159). Hence, the mother recognizes her own past limitations in responding to the daughter.

> *Up until this all happened I never really realized what a shy person you have been all your childhood, sweetie-pie. I guess that's because I have not been a very good listener – always wanting to interrupt. I will try to be a better mother... I am too controlling and expect way too much from you. . . I have been told that perhaps I should take a parenting course because I don't seem to know how to be firm enough as a mother."* (CHM 16)

Dear Daughter,

You must realize that the food you seem to be eating is not very much. The meal you had with me was a much smaller serving than the average adult meal served in a restaurant. If you choose to pick at your food, hide it, pretend to swallow it and spit it out later, the nurses at the hospital will realize this and revert back to tube-feeding.

I don't believe you are gaining hardly any weight, if any, since you went off the tube-feeding; however, as long as you have the anorexic behavior of denying yourself enough food to keep you going, you will go back down to rock bottom if you resume normal behavior, like school, going for a job etc. I think your health team realize this and that is why they are so cautious with your privileges to go home or to the mall or whatever.

However, we must try to be positive. You have not always had this attitude about eating and in the future I am hopeful that you will find positive things to control in your life. You have many talents that many do not have. You are extremely intelligent, artistic, caring and pragmatic. I know throughout your short life you learned how to do more things that many people do not do in their entire life-time. I am an optimist and believe that you will beat this eventually, especially when you have so many people trying to help you. I love you, sweetie pie. Good night and sleep well.

Love

Mom

Figure 1. Letter to Daughter about behaviours contravening recovery

The mother identifies herself as "*no expert on this health problem [AN]"* (LM 7). Nonetheless, she recognizes her daughter's inability to *"take control of this situation"* (LM 23) and the lack of experience of the treatment team who *"do not see that many anorexics and ... probably [find it] hard to understand what they should do"* (LM 26). The mother relates to her daughter first as confidant or social equal and second as worried parent encouraging her daughter to accept the medical approach even when it is inadequate because it is *"all that is available"* (LM 7).

F. *Ethic of repair*

Out flowing from taking stock, the mother enacts an ethic of repair to help heal past and present elements influencing any mother-daughter division. She empathizes with the daughter through such messages as *"I understand you're upset about losing passes"* (LM 26) and *"It must get frustrating to you to continue to eat quite a bit of food and not be active"* (LM 30). She tries to normalize and justify her daughter's experiences.

> *I can understand how it is difficult to accept all the controlling features of your program because people your age are at a stage when they try to rebel against adults telling them what to do (even if it is for their own good).* (LM 7)

According to Murdoch [33], mother-daughter division is based on having separated self from feelings and spiritual nature. This imbalance of values within self and culture calls for re-investing in the depth and truth of human experience to restore authenticity and healing. The mother is

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moved to take reparative action by intervening with the treatment program.

I think that you are right about one thing and that is that at times your contract is not understood very well by your nurses and by us- this new one seems to have changed a lot of things you used to love and did not really state in it that you no longer had these privileges. It probably should have said that just to make things less confusing. It doesn't seem quite right that you would have to drink two cans of ensure in one block of time either. Your stomach can only hold so much food. This needs to be corrected as well. I am just thankful that it is food, not medication they are making mistakes about. (LM 29)

The mother expresses guilt and apologizes about aspects of her own care-giving, for example, not realizing her daughter was not ready to take her driving test [LM 46] and asking her daughter to try on clothing that was too small [LM 37]). *"I'm sorry if I said anything that made you feel sad. I'm also sorry that I am pushing you too much to do things that I want you to do instead of things that you want to do"* (LM 46). The mother's distress is gut-wrenching to read. "Oh you whom guilt does not condemn" [32] (Canto XXVIII, Line 70).

The mother's support of her daughter within the ethic of repair differs from that within drawing strength in that the goal of drawing strength is to have the daughter gain confidence and be seen in a positive light. The ethic of repair focuses on helping the daughter reduce and integrate the pain of the eating disorder, its treatment, and life's general hurts.

F. Fending off the beast

The mother feels impotent against the beast of "*deadly starvation*" (LM 33) and "*continually at the mercy"* of the anorexia (LM 29). In the words of Dante, "Everywhere I looked, the beast was there blocking my way. ... Furious with hunger … [and] wracked with every kind of greediness ... How many people has she brought to grief! [32] (Canto I, Lines 34-35, 47, 50-51).

The mother recognizes that although intertwined with her daughter, the AN must be perceived as an entity separate from her daughter. Thus she tells her daughter, "*You are loved by many people, both relatives and friends. You – not this imaginary person that your anorexia wants you to be"* (MI). The mother confronts the anorexic behaviors as external to her daughter yet something for which the daughter must take responsibility, admonishing the "deadly" starvation

Will drive you to kidney failure or a heart attack. Your anorexia recognizes that your body is still at a very weak state physically. It is possible that when you thought you could run up those stairs to the third floor that you could very well have had a heart attack. If I did not prevent you from doing that, it is not far-fetched to believe that you could have died this afternoon. (LM 33)

As stated by Murdock [33] , the heroine confronts "ogres" and adversaries, and in doing so "she encounter[s] the forces of her own self-doubt, self-hate, indecisiveness, paralysis, and fear" (p. 48). Taking action, the mother discusses her concerns with the treatment team about "having so many supplemental drinks beside the regular meals," concluding that the team's approach seemed to be contributing to the daughter emerging vomiting (LM 30) and the family's confusion.

From what we can tell, your team has decided that they must do something about your weight, even though they have been focusing on your behavior. You were rewarded in the past weeks for your excellent behavior of eating your meals and limiting your exercise. The only problem now is that you are just as frail as you were quite a few weeks ago. I think they realize that the rewards they gave you (e.g. 30 minutes off the unit every day, 2- two hour passes, and an overnight pass) all contributed to you staying frail. (LM 29)

The mother's efforts help the daughter to contemplate taking greater personal accountability toward recovery. According to the daughter, *"when I read stuff like my mom thought I was more fragile than I thought I was ... it struck me she was talking to me versus the anorexia. That's when I got upset* (Interview with Daughter [DI]).

The mother joins forces with her daughter, telling her daughter "*Don't fall into the trap of wasting your time on who you wish you were. You have developed into a lovely person"* (CHM 33). The mother praises her daughter's efforts to resist the eating disorder, while speaking out against treatment practices that reduce the daughter's autonomy and opportunity to learn.

G. Homecoming

"We are coming home. We are woman. We are coming home" [33] (p. 129). The mother reassures her daughter that it is more *"exciting"* (CHM 36) in the outside world than in the hospital and that there are many totally *"cool"* things to do (CHM 14). Although there are still issues that need to be worked on, the whole family wants the daughter to be able to come home and enjoy life [LM 40]. The mother explains to the daughter they will together *"plan out your meals for the days to come so there will be no surprises"* and no reason to get *"stressed out"* (CHM 35). The mother is reaching out to her daughter where the daughter is at, providing appropriate assistance for the daughter to continue to relinquish the eating disorder.

Dear Daughter, You are wonderful daughter and I appreciate that you are trying so hard to slowly integrate back into the home ... We are all here to fight this disorder with you, but in the long run you need to gradually change your way of thinking, which can be destructive to your health. This is going to take a very long time and no one expects you to quickly recover. We will just take baby steps, by having very similar meals that you have had in the hospital, trying not to overdo any type of physical activity, etc. because none of us, including you, want to see your health go back downhill.

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I believe in you and know that with help you will gradually overcome this. I love you, sweetie pie. Love Mom XXX OOO (LM 48)

The mother described herself during the daughter's second hospitalization as developing a *"more active role, especially when she [the daughter] was released"* (MI). The mother met with the team in establishing the home protocol. She was directed to "*take over the role of the Licensed Practical Nurse"* in sitting with her daughter while she was eating because *"they believed back then that if I didn't do that, then she [daughter] would probably just go back into the hospital"* (MI). Consequently, the mother did sit with her daughter; however, she identified later that this action served as a source of worry and conflict upon realizing she was interfering with her daughter's autonomy and self-care. The mother was able to articulate her concerns with her daughter's therapist and gradually decrease this level of control. "We climbed ... until ... ahead of us I saw some of the lovely things the heavens hold, and we came out to see once more the stars" [32] (Canto XXXIV, lines 135-139).

VI. DISCUSSION

Parent involvement in treatment is considered efficacious for adolescent clients with eating disorders [34, 35, 36. 37, 38]. Moreover, Weaver [13] reported that parents wanted to be included in treatment team decision making and to contribute their hard earned knowledge of caring for their child to help guide treatment and homecare strategies. Yet, despite this movement toward family-informed care, there is a paucity of literature about family's private perspectives concerning institutional treatment for eating disorders. This study is significant in that it conveys a real-life situation previously not possible to study as the cards and letters were written for private rather than research purposes. The study therefore provided for the discovery of new information relevant to the care of those affected by eating disorders.

The findings of this narrative study contribute understanding of maternal responses to the enigma and treatment of eating disorders. The notion of a parent being lost alongside her daughter is provoking. The findings help account for the seemingly contradictory nature of maternal involvement in relinquishing control of a child with an eating disorder to hospital care. For example, in seeking a clearing, the mother appeared engaged in tasks not obviously related to her daughter's recovery like preparing her personal income tax. In drawing strength, the mother profusely praised her daughter's accomplishments even though her daughter did not meet treatment goals. Taking stock, the mother indicated awareness of problems within the treatment approach. In ethic of repair, the mother called for greater accountability of the treatment team and began to take action to correct inconsistencies in the treatment regime. In fending off the beast of AN, the mother confronted her daughter's anorexic behaviors while continuing to enhance her daughter through complimenting non-anorexic behaviours and accomplishments. Homecoming, although outwardly a time of celebration, was also a time of worry as the mother resumes for a time full responsibility for helping her daughter effect recovery. These various responses appear contradictory for they occur non-linearly along the differing threads comprising the core narrative of lost alongside. Understanding this complex nature of lost alongside my daughter can help health professionals interpret contradicting parental behaviors and intentions.

The mother's experience is complementary to the dominant clinical narrative that a daughter's recovery is dependent on the mother and rest of the family forming a therapeutic alliance with the treatment team. In this study, the mother was blamed by the treatment team for not setting limits on her daughter's behaviours. This is the dominant narrative ─ the team knows best and parents and daughters must comply with established treatment (and parenting) protocols. Although the mother initially supported the treatment team's approach, she learned to ally herself with her daughter upon recognizing the limitations of the team approach. The mother did help her daughter to recover and, in providing a "critical piece of the care-giving puzzle" [39] (p. 8), the mother gained a sense of efficacy that she and her daughter could change the situation irrespective of the dominant narrative.

Health professionals are increasingly recognizing the value of a narrative approach. For example, Charon [40] has articulated how knowledge otherwise unobtainable emerges when physicians think "narratively" about their patients. In this study, the development of the lost alongside narrative provided valuable insight into maternal perspectives about hospitalization and care. Our represented narrative validates the mother's struggle to care for her daughter and can help inform the development of client and family centered interventions.

The credibility of narrative research is questioned by those who equate it with embellishment and persuasion [41]. For this reason, we have stringently monitored the rigour of this research process and product. The quality of our findings was enriched through regular and intensive discussions of the composition and meaning of the emerging narrative threads. Our sustained efforts to collect extensive, converging, relevant evidence through seeking narratives from both mother and daughter aided interpretation of findings. Among the criteria for maintaining rigour in narrative search are verisimilitude (truth-like quality), integrity, and compellingness. We enhanced verisimilitude through taking drafts of and direction for the research product to our participants, the mother and daughter. We conducted the analyses independently and then collaboratively. As we represented their experiences, we determined they were most qualified to evaluate the integrity of the analysis. We presented compelling evidence with data excerpts consistently linked to each narrative thread so readers can independently judge the strength of our analyses.

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We attempted to communicate the findings in an engaging manner that invites reflection and dialogue. Although of ancient origin and prepared from a male perspective, Dante's literary construction of finding himself lost, confused and terrified is, we think, helpful to understanding the mother's experience. The more modern heroine's journey by Murdock added knowledge of the need for introspection and openness to self-work in struggling against the Patriarchy (i.e., the distant treatment team) in her quest to grow stronger in her ability to create her own destiny while helping her daughter. From having descended into the baffling depths of her daughter's disorder and treatment, she struggled to connect with her daughter and from there to spark authentic recovery with herself as her only mentor. The mother grew from these experiences and the insight generated provides a deep understanding of parental role.

VII. CONCLUSIONS

The perspective of the mother, particularly when combined with that of the daughter, offers a comprehensive rendering of individual experiences not evident within the professional literature. Indeed most accounts available for parents are written by therapists or physicians and lack the critical "voice" of parents [39]. Thus, the findings of this study complement the dominant clinical narrative, and can inform practice by allowing understanding of real-life experiences and the meanings that patients and families draw from these experiences. The mother-daughter relationship and communication provide a critical piece of the puzzle of eating disorders and recovery. Health professionals might better understand and help clients and families by hearing their stories of their tumultuous experiences. We call for ongoing narrative research to lift up non-dominant, complementary versions of recovery identifying them as legitimate and understandable narratives to stand alongside the dominant clinical narratives of disorder and recovery.

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REFERENCES

[1] Canada Parliament, "Eating Disorders among Girls and Women in Canada," Report of the Standing Committee on the Status of Women & Hélène LeBlanc (Chair). 41st Parliament. 2nd Session. November 2014. http://www.parl.gc.ca/content/hoc/Committee/412/FEWO/Reports/RP6772133/feworp04/feworp04-e.pdf

[2] T.D.Wade, A.Keski-Rahkonen, and J. Hudson, "Epidemiology of Eating Disorders," in Textbook in Psychiatric Epidemiology, 3rd ed., M. Tsuang and M. Tohen, Eds. New York: Wiley, 2011, pp. 343-360.

[3] Renfrew Center Foundation for Eating Disorders. "Eating Disorders 101 Guide: A Summary of Issues, Statistics and Resources," 2003 http://www.renfrew.org

[4] Canadian Mental Health Association, "*Facts about Eating Disorders," 2014*.http://www.cmha.ca/mental_health/facts-about-eating-disorders/#.Ux9ce4XdBPE

[5] S.J. Crow et al., "Increased mortality in bulimia nervosa and other eating disorders," Am. J Psychiatry, vol. 166, 2009, pp. 1342-1346. doi: 10.1176/appi.ajp.2009.09020247.

[6] B.J.Blinder, E.J.Cumella, and V.A.Sanathara, "Psychiatric comorbidities of female inpatients with eating disorders," Psychosom Med, vol. 68, 2006, pp. 454-462. doi: 10.1097/01.psy.0000221254.77675.f5

[7] V. Forman-Hoffman, M. Mengeling, , B. M. Booth., J. Torner. and A.G. Sadler, "Eating disorders, post-traumatic stress, and sexual trauma in women veterans," Milit Med, 177(10), 2012, pp. 1161-1168.

[8] T. M. Gadalla and N.Piran, "Eating disorders, substance use disorders and major depression in the Canadian population." J Ment Health, vol. 18, 2009, pp. 486-494. doi: 10.3109/09638230902968241

[9] E. Attia and B.T. Walsh, "Behavioral management for anorexia nervosa," N Engl J Med, vol. 360, 2009, pp. 500-506. doi: 10.1056/NEJMct0805569

[10] E.J. Button, B. Chadalavada, and R.L. Palmer, "Mortality and predictors of death in a cohort of patients presenting to an eating disorder service," IJED, vol. 43, 2010, pp. 387-392. doi: 10.1002/eat.20715

[11] S.A. Trent, M.E. Moreira, C.B. Colwell, and P.S. Mehler, "ED management of patients with eating disorders," Am J Emerg Med, vol. 31, 2013, pp. 859-865. doi: http://dx.doi.org.proxy.hil.unb.ca/10.1016/j.ajem.2013.02.035

[12] J.T. Suokas et al., "Suicide attempts and mortality in eating disorders: A follow-up study of eating disorder patients," Gen Hosp Psychiatry, vol. 36, 2014, pp. 255-257. doi: http://dx.doi.org/10.1016/j.genhosppsych.2014.01.002

[13] K. Weaver, "Loving her into well-being one day at a time: Narratives of caring for daughters with eating disorders," OJN, vol. 2,2012. pp. 406-419. doi: 10.4236/ojn.2012.24059

[14] R. McMaster, B. Beale, B., S. Hillage,, and S. Nagy, "The parent experience of eating disorders: interactions with health professionals," Int J Ment Health Nurs, vol. 13, 2004, pp. 67-73. doi: 10.1111/j.1447-0349.2004.00310.x

[15] H.G. Lerner, H.G. Women in therapy. New York: Aronson, 1988.

[16] S. Minuchin, B.L. Rosman, and L. Baker. Psychosomatic Families: Anorexia Nervosa in Context. Cambridge: Harvard University Press, 1978.

[17] I. Dancyger, V. Fornari, L. Scionti, L., W. Wisotsky, and S. Sunday, "Do daughters with eating disorders agree with their parents' perception of family functioning?" Compr Psychiatry, vol. 46, pp. 135-139, 2005. doi:10.1016/j.comppsych.2004.07.024

[18] D. Benninghoven, N. Tetch, S. Kunzendorf, and G. Jantschek, "Body image in patients with eating disorders and their mothers, and the role of family functioning," Compr Psychiatry, vol. 48, pp. 118-123. doi:10.1016/j.comppsych.2006.08.003, 2007.

[19] J. Canals, C. Sancho, and M.V. Arija, "Influence of parent's eating attitudes on eating disorders in school adolescents," Eur Child Adolesc Psychiatry, vol. 18, pp. 353-359. doi: 10.1007/s00787-009-0737-9, 2009.

[20] A. Coffey, and P. Atkinson, "Narratives and stories," in Making sense of qualitative data: Complimentary research strategies, pp. 54-82. Thousand Oaks, CA: Sage, 1996. http://academic.son.wisc.edu/courses/n701/week/Narrativesandstories.pdf

[21] N. K. Denzin, Interpretive interactionism. Newbury Park, CA: Sage, 1989.

[22] Y. D. Eaves and D. L. Kahn, „Coming to terms with perceived danger," JHN, vol. 18, 2000, pp. 27-45. doi: 10.1177/089801010001800105

[23] J.W. Creswell, Narrative research designs. In Educational research: Planning, conducting and evaluating quantitative and qualitative research, 3rd ed., pp. 511-550, Upper Saddle River, NJ: Pearson, 2008.

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[24] M. Cole, “Qualitative research: a challenging paradigm for infection control,” Journal of Infection Prevention, vol. 7, 2007, pp. 25-29. doi: 10.1177/14690446060070060701

[25] K. Weaver and J.K. Olson, “Understanding paradigms used for nursing research,” J Adv Nurs, vol. 53, 2006, pp. 459-69.

[26] M.Q.Patton, Qualitative research and evaluation methods, 3rd ed, Thousand Oaks, CA: Sage, 2002.

[27] T. H. Schram, Conceptualizing and proposing qualitative research, 2nd ed., Upper Saddle River, NJ: Pearson, 2006.

[28] C. Emden, (1998) “Conducting a narrative analysis,” *Collegian*, vol. 5, pp. 34-39. doi:10.1016/S1322-7696(08)60299-1

[29] D. Polkinghorne, Narrative knowing and the human sciences. Albany, NY: State University of New York Press, 1998.

[30] M. Cortazzi, Narrative analysis. London: Falmer, 1993.

[31] J.M. Morse and J. Singleton, “Exploring the technical aspects of "fit" in qualitative research,” QHR, vol. 11, 2001, pp. 841-847. doi: 10.1177/1049732304265959

[32] Dante Alighieri. *The Divine Comedy,* translated by Henry F. Cary. Vol. XX. The Harvard Classics. New York: P.F. Collier & Son, 1909–14; Bartleby.com, 2001. www.bartleby.com/20/.

[33] M. Murdoch, The heroine's journey: Woman's quest for wholeness. Boston: Shambhala, 1990.

[34] I. Eisler,, C. Dare, M. Hodes, G. Russell, E. Dodge, and D. Le Grange, “Family therapy for adolescent anorexia nervosa: The results of a controlled comparison of two family interventions,” J Child Psychol Psychiatry, vol. 41, 2999, pp. 727–736. doi:10.1111/1469-7610.00660

[35] K. K. Godfrey, “Just one more bite: a qualitative analysis of the family meal in family-based treatment for anorexia nervosa,” Eur Eat Disord Rev, vol. 23, 2015, pp. 77-85. doi: 10.1002/erv.2335

[36] J. Lock, “Evaluation of family treatment models for eating disorders,” Curr Opin Psychiatry, vol. 24, 2011, pp. 274–279. doi:10.1097/YCO.0b013e328346f71e

[37] J. Lock et al., “Randomized clinical trial comparing family-based treatment with adolescent-focused individual therapy for adolescents with anorexia nervosa,” Arch Gen Psych, vol. 67, 2010, pp. 1025–1032. doi:10.1001/archgenpsychiatry.2010.128

[38] A. Smith, and C. Cook-Cottone, “A Review of Family Therapy as an Effective Intervention for Anorexia Nervosa in Adolescents,” J Clin Psychol Med S, vol. 18,, 2011, pp. 323-334. doi:10.1007/s10880-011-9262-3

[39] C. Dellasega, “ The starving family: Caregiving mothers and fathers share their eating disorder wisdom”. Fredonia, WI: Champion, 2005.

[40] R. Charon, "Narrative medicine: Form, function, and ethics." AIM, vol. 134, 2001, pp. 83-87. http://www.annals.org/content/134/1/83.full.pdf

[41] T. D. Glover, "The story of the Queen Anne memorial garden: Resisting a dominant cultural narrative," J Leisure Res, vol. 35, 2003, pp. 192- 212.

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