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Family Memoirs

I Yelled At My Mother: Narrative Introspection into the Multifaceted Emotions of Sympathy & Compassion in Care-giving

Sympathy, empathy and compassion have been widely studied in many different disciplines but there has been little agreement among researchers. Studies often address the process of giving sympathy but little has been done with the process of receiving sympathy or the complex intersection of the two. This paper is an autoethnography that explores the relational way we develop an understanding of sympathy and compassion. I use an introspective process to study how I have come to understand compassion and sympathy in care giving for my mother. I seek a different approach to compassion and sympathy as a social process of symmetry and connection rather than of hierarchy or power. It is in finding loving kindness for myself that I strive to extend compassion to others without condescension. In Start Where You Are: a Guide to Compassionate Living Pema Chödrön advocates for a change in the traditional way we view sympathy and compassion as the helper and the one in need of help; "In order to have compassionate relationships, compassionate communication, and compassionate social action, there has to be a fundamental change in attitude" (p. 103). Through the narratives in this paper I seek to create evocative stories which will induce emotional responses for the readers in the hope that they will experience sympathy and compassion in a different way.

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Introduction

A simple question like “How’s your Mom?’ was packed with meaning. I experienced deep, unfamiliar emotional responses as many different people asked me this simple question each day. I had never undertaken care giving for an aging, seriously ill parent. I had never received such sustained and pervasive sympathy and compassion. I decided to conduct a research study of this new world because I was seeking a way to understand the events, emotions, and interactions. This paper is my autoethnography of a process of discovery in the relational way we make meaning and develop understanding of emotions. I use introspective techniques and narratives to explore sympathy and compassion. The introductory narrative shows a moment when I realize that both my mother and I are more comfortable in offering sympathy than receiving it. It is a moment when the most basic research question is formed. How do we understand the complex layers of the social process of communicating sympathy and compassion? The movement between the backstage of care giving and the front stage of my public routine is important to this research. The middle sections of this paper take the reader from my mother’s bedroom in the middle of the night to the conversations in the halls of the university. These narratives juxtapose the intensity of care giving with the routines of day-to-day interactions. I share my struggles to bridge these two spaces. I find myself at a loss in both spaces. I strive to organize the chaos of illness. I try to find the words to convey my experiences and respond to the sympathetic comments of others. Throughout these experiences I question why I respond in the way that I do. The concluding section of this paper includes a narrative about finding compassion for myself in a moment when I am least compassionate with my mother. The paper ends with my reflections on the practice of understanding multifaceted emotionality. My goal is research that “authenticates the novelty, creativity, and complexity of human relationships” (Bochner, Ellis, Tillman-Healy, 1998, p. 47).

Giving in the Act of Receiving

Her face becomes contorted and a low whine escapes her lips as she resists tears. "I'm just a useless burden. Why won't God take me? You can't possibly understand what it feels like to be so helpless, so dependent on everyone," my Mom says. She runs her hands through her thin streaked white, gray, brown hair and adjusts the thin oxygen tube in her nose. "I can't get my breath!" She gasps and then draws air deeply into her nose, purses her lips, and exhales as if blowing out candles on a birthday cake. "I can't fix my own lunch, can't get a glass of water, or bend over when I drop something. I can't even go to the bathroom by myself!" Mom's voice moves from resigned and sad to louder and more frustrated. She becomes agitated, her leg shakes, and her hand is clenched around her brown wooden rosary from Italy.

I feel a cold wave deep inside my chest because Mom so seldom complains even when the pain is overwhelming. I share her despair as I look into her blue eyes clouded by cataracts. We have lived through the chaos of a slowly debilitating terminal illness for several years. I share Mom's feelings of sadness, frustration, and grieving for the way life used to be for both of us. I don't know how to respond so I hold her hand and sit quietly for a few moments. As I caress her hand I think of how the doctors frequently caution that her skin is "fragile." It just feels extra soft to me, but I know Mom hates the large red and purple splotches that seem to appear for no reason on her arms and hands. Mom's hearing has deteriorated as she becomes weaker so our "conversations" are often conducted on a small spiral notepad with thick a black pen. I print in reply,

> YOU ARE RIGHT - I DON'T KNOW WHAT IT FEELS LIKE. BUT YOU DON'T EITHER. YOU WERE ALWAYS THE HELPER. YOU HELPED YOUR FRIENDS, YOUR SISTERS, THE NEIGHBORS, TEACHERS AT SCHOOL, AND CHURCH GROUPS. EVERYONE LOOKED TO YOU FOR HELP. YOU WERE THE STRONG ONE WHO COULD SOLVE A PROBLEM OR FIND TIME TO DO WHATEVER WAS NEEDED.

As Mom reads what I wrote, I am flooded by memories of all the things my Mom did to help her friends with big problems and small ones. If any of the neighborhood kids got hurt playing they would come to our house to see Nurse Mary for first aid, a Popsicle, a hug, and words of encouragement.

Mom sits up a bit straighter in her wheelchair as she reads my words. I continue writing in the notebook and hand it to Mom,

> MAYBE GOD WANTS YOU TO LEARN HOW TO TAKE HELP FROM OTHERS NOW. MAYBE THAT'S THE LESSON YOU MUST LEARN BEFORE HE TAKES YOU TO HEAVEN. YOU KNOW HOW TO HELP – YOU ARE GOOD AT THAT. BUT MAYBE THAT'S EASIER FOR YOU THAN ACCEPTING HELP.

I surprise myself by what I've written. I hadn't planned to write this. I do not remember consciously thinking this about Mom, but it sounds like something springing from my Catholic school days. There is alertness in my body because I feel like I've experienced almost a revelation about my Mom and maybe about myself as well.

"You are such a smart daughter," Mom says with her typical stream of compliments. "I guess that could be my lesson, and it sure isn't easy. I'll pray for the patience to accept help. I think I have a good prayer in this month's Missalette." Mom rummages through her basket of papers on the shelf next to her daily wheelchair "spot" at the dining room table. She pulls out her prayer book and her magnifying glass then flips through the pages and finds a prayer and a hymn from St. Francis of Assisi. "Here, read this she says."

> Grant that I may never seek
> So much to be consoled, as to console,
> To be understood, as to understand,
> To be loved, as to love with all my soul.
> Make me a channel of your peace.
> It is in pardoning that we are pardoned,
> In giving of ourselves that we receive,
> And in dying that we're born to eternal life. (p. 278)

Mom and I are both quiet for a few moments. I nod at her and decide not to write what I'm thinking; *this passage is* *still* *about giving*. Then I realize that we are all connected. While the prayer says we receive in our giving, it implies that we also give to others in our receiving.

Mom interrupts my thoughts, " I guess if I let others help me they'll get God's grace, so I'll be helping them." I smile as Mom continues, "You know, I never thought I'd get so feeble. I know it isn't easy for you either. I worry that I'm asking too much from you." Mom caresses my cheek.

I respond by writing, YOU SPOILED ME. YOU TOOK CARE OF ME FOR MANY, MANY, MANY, MANY YEARS. AND WE BOTH KNOW THAT I WASN'T AN EASY KID. NOW IT'S MY TURN TO SPOIL YOU. THAT'S THE WAY IT IS SUPPOSED TO BE. We both chuckle as we read the pad together.

"I guess that's the way things are supposed to be. I don't know what I would do with out you, my oldest, my Little Miracle," she smiles and jokes.

DON'T WORRY I'LL STAY WITH YOU UNTIL GOD CALLS YOU TO HEAVEN. YOU CAN STAY AT HOME. I'M YOUR HELPER, SECRETARY, BOOKKEEPER, NURSE, CHAUFFER, COOK -- YOU NAME IT. I write and Mom pats my arm. Tears come into my eyes because I feel so sorry for her, because I love her so much, and maybe because I wonder if I'll be able to keep my promise until the very end.

Okay, now let's have Happy Hour, and don't water down my cocktail tonight, young lady!" Mom says with more vigor in her voice. I walk to the kitchen pantry to get Mom's vodka, and as I make her drink I see Mom re-reading the pages of the spiral notebook.

Methodology

This paper is an introspective autoethnography about the multifaceted emotionality of experiencing sympathy and compassion. It involves a relational view of the social process, not just giving or receiving sympathy but the recursive nature of these emotions. My research is the result of my role as a caregiver to my Mother for three years. When I began compiling notes, exploring my perceptions and feelings, I thought the paper was about the emotional difficulty of talking about impending death with those not in the experience. I started my research by looking at the differences between conversations with my Mother about her approaching death and interactions with my friends and colleagues. As Carolyn Ellis writes, dying is “not a world that is openly accessible to visitors…When you are inside IT, it’s hard to imagine there’s a world outside IT. When you’re outside IT, you can’t fathom life on the inside, even when you’ve been there before and know you’ll be there again” (Ellis, 1995, p. 81). As my research progressed, I started to be more aware of what I said to people when they asked me “How’s your Mom?” I kept field notes on the private events at home and the public interactions with friends and colleagues, primarily at the university. In addition to using writing as inquiry (Richardson) and analyzing my field notes, my data includes spiral books of notes we have written to my Mother on a daily basis throughout the past three years because she is severely hard of hearing and has cataracts.

As I became more aware of my feelings about receiving sympathy, this led to a broader analysis of the intersubjectivity of the experiences. I expanded my study to look at how I constructed, experienced, and came to understand compassion. Death-talk, illness and care-giving all remain an important background to my research; however, I focus on multiple levels and meanings of my emotional interactions in giving and receiving sympathy and compassion. How did I feel and why did I experience these emotions when people expressed concern for my Mother? During the process of my introspective writing and conversations with colleagues, friends, and family my inquiry spawned related questions: How did my Mother and I feel about receiving sympathy and assistance? Did I experience these emotions in the same way as my Mother?

My research was more than just personal reflection, but introspection as described by Ellis:

> Introspection then is a social process as well as a psychological one. It is active thinking about one's thoughts and feelings; it emerges from social interaction; it occurs in response to bodily sensations, mental processes and external stimuli as well as affecting these same processes. It is not just listening to one voice arising alone in one's head; usually it consists of interacting voices, which are products of social forces and roles. (Ellis 1991, p. 28-29)

I use narrative methodology because I want to communicate a sense of the lived reality. My goal is to create evocative narratives that depict people involved in complex struggles and explore the way people seek to understand their struggles. These narratives show people who are "trying to restore the continuity and coherence of life's unity and values in the face of unexpected blows of fate. … The word evocative contrasts the expressive and dialogic goals of this work with the more traditional orientations of mainstream representational social science" (Ellis and Bochner, 2000, p. 744). The narrative methodology is particularly well suited to my research since evocative stories seek to induce an emotional response. The subjectivity of my lived experience hopefully will lead the reader to identify commonalities in their lives (Ellis & Flaherty). I selected the storied moments in this paper based on personal introspection as a sensemaking method. Since sensemaking is an on-going process, it never stops or starts. Yet stories have beginnings and endings because we formulate stories to create some sense of coherence to events in our lives. Our stories are the moments in time when meaning comes together for an individual or groups of individuals. Weick asserts that, "To understand sensemaking is to be sensitive to the ways in which people chop moments out of continuous flows and extract cues from those moments" (p. 43).

I embrace an empathetic stance in my research. Often researchers use this term to describe a dialogic relationship with the knower and the known, researcher and subject, or researchers and co-researchers. “Empathy becomes an attitude of attention to the real world based in an effort to connect ourselves to it rather than to distance ourselves from it” (Josselson, p. 31). As I explored sympathy and compassion, my personal revelations came from learning about the Buddhist practice of starting with compassion for oneself in order to extend compassion to others. This empathetic view is where I start and end.

Literature Review

We are sipping our third glasses of raspberry ice tea, sitting in the black vinyl booths of Jan’s Deli near campus. I’m leaning forward against the chrome table edging to hear Carolyn’s responses to my proposal for a paper in her Communicating Emotions class.

“Sounds like you have been thinking deeply about your paper –and feeling deeply. Has it been difficult to write about your Mom?” Carolyn begins gently.

“Sometimes, it is emotional but I’m also energized now that I’ve found the real topic of the paper, not death talk but rather sympathy, compassion, empathy. The subtleties of the terms and how people have studied them are intriguing. It’s the right time for me to explore it on personal level.”

“So tell me about what you’ve been reading and thinking,” Carolyn invites me to talk through my ideas. I pull out my notes and outline of my literature review.

“The literature search yielded massive results on the topic so it was not easy to focus and weed through the most relevant work. I began by re-reading Arthur Frank’s <u>The Wounded Storyteller</u>. Frank sees illness as a call for stories. In some senses I experienced the “chaos narrative” of illness that Frank describes as hard to tell in words and also difficult to hear. Frank concludes that “Each suffering is part of a larger whole; each suffering person is called to that whole, as a witness to other sufferings" (p. 179). Illness and care giving is not my unit of study, but Frank's work does address the social aspects of the topic. Social structure, social process, and deep intersubjectivity are critical to the construction, experience, and understanding of emotions. As Candice Clark explains, "Sympathy is a crucial emotion that provides the glue for social bonds, the building blocks of society…sympathy reinforces and creates social bonds" (Clark, p.5).

In my introspective research I personally felt Hochschild's' "pinch", a discrepancy between the emotions I experienced, what I wanted to feel, and what I thought I should feel (p. 56). I was engaged in managing my emotions, but even more I was in an intense situation that I had never experienced before, in uncharted territory. I was trying to find and read the map that would tell me how to journey through the different spaces. I would characterize myself as a highly empathetic, compassionate person who extended sympathy in many ways to others. I learned much of this from my Mother. However, when I was faced with receiving sympathy and compassion from others I began to re-think my identity and explore how we receive sympathy and compassion.

Another Country by Mary Pipher addressed emotionality in relationships with the elderly so it was valuable background especially as I looked at interactions. Our class readings from Goleman's Emotional Intelligence pulled some of the literature and my experiences together, "Empathy builds on self awareness, the more open we are to our own emotions, the more skilled we will be in reading feelings" (p. 96). Goleman elaborates on the various studies done on how children develop empathetic behaviors. A study at the National Institute of Mental Health showed that children who saw empathetic reactions from their parents and discussed consequences in others learned to imitate these experiences as they learned to develop an array of their own empathetic responses (p. 99). Goleman led me to look more deeply at my Mother's perceptions of sympathy and empathy.

The topics of sympathy, empathy, and compassion are widely studied in many different fields by many different methods including cognitive, emotional, and physical aspects of the topic. Researchers have reached different conclusions and not found general agreement. In 1996 Duan and Hill reviewed "The Current State of Empathy Research" in social and developmental psychology and concluded that even with the great deal of research done, we still have limited knowledge of empathy. There had been a lack of effective tools and that researchers needed to distinguish between "intellectual empathy" and "empathetic emotions." 1997 Candice Clark wrote a comprehensive work, Misery and Company, which explored the social character of sympathy, theorized about the process of sympathy, proposed rules of sympathy, and addressed the microhierarchy and micropolitics of the topic. Clark studied how people in everyday settings defined and expressed sympathy, explaining the individual and social consequences of sympathy. I was tempted to apply Clark's steps and rules to my experiences because in some ways the categories fit so well but I just felt there was something missing for me. Clark's structure did not fully resonate with my experiences.

In 2001 Kerem, Fishman and Josselson studied how the theoretical differences of empathy as cognitive, affective, or multidimensional found expression in experience of everyday relationships. They point to the difficulties in defining empathy and sympathy and the importance of their findings that it means different things to different people—in both giving and receiving. They also suggest that receiving sympathy is an area of research that has been neglected. In the same way researchers such as Planalp and Fitness call for a more integrated approach to studying emotions in social and personal relationships. Planalp and Fitness point to the differences in cultural approaches to emotions, particularly from Eastern and Western standpoints. Rather than rigid distinctions, cognitive or affective, they call for more synergistic, symbiotic approaches to understanding emotions.

Emotions and sympathy in particular may be described in terms of power and hierarchy, who is one up and who is one down, giving or receiving. However, if we look at relationships in terms of respect as posed by Lawrence-Lightfoot, we strive to achieve symmetry and a sense of connection, trust among equals. With that premise I constructed a different approach to empathy, sympathy, and compassion as a social process, perhaps a more Feminist approach. I found a unique comparison by Western scientists and Tibetan Buddhists, Visions of Compassion, based on a conference to explore differences. Western sciences start with the external and position rational thinking as the control necessary to manage the unruly emotional side of human nature. The Eastern Buddhist beliefs do not hold a mental and material division but rather stress an internal sense of human nature based on compassion and connections to others. In the Art of Happiness (1998) the Dalai Lama explains that in the West compassion may be seen as a burden, but he knows it has a freeing, positive effect. In Ethics for the New Millennium (1999) the Dalai Lama called compassion the ‘supreme emotion’, not just spiritually important in the world’s major religious traditions but also “fundamental to the continued survival of the species” (p.130).

The final stop in my journey to understand and narrate compassion for this research paper was Start Where You Are: A Guide to Compassionate Living by Pema Chödrön. She describes compassionate action, “It starts with loving-kindness for oneself, which in turn becomes loving-kindness for others” (p. 101). This brings a connection or a kinship that avoids dualism or any sense of condescension. She calls our sense of separateness, “a funny kind of mistake.” Chödrön advocates for a change in the way we view sympathy and compassion as the helper and the one in need of help. “In order to have compassionate relationships, compassionate communication, and compassionate social action, there has to be a fundamental change in attitude" (p. 103). As I read Pema Chödrön's work I could see myself in between worlds, vacillating between the common dualistic perceptions but seeking the integrated view of sympathy and compassion.

So I started by looking at how people responded to my death talk, then how I was in different interactions of death talk. Next I began looking at how people expressed sympathy to me, and how I reacted to the communication. Finally I developed an awareness of the mutuality in giving and receiving compassion."

"Good I'm glad you didn't get bogged down in definitions," Carolyn replies. "Your introspective work will make this paper work best. You've got a feel for the topic and the relevant literature, now begin writing the stories – or I guess I should say continue writing, begin editing, rewriting. It is all in the process and your paper will model the process of research as introspective discovery."

Stories of Empathy, Sympathy & Compassion

Behind the Scene: Seeing in Darkness

I am sleeping lightly so I quickly respond when I hear the bell in Mom's room. I also hear the strangled sounds of her labored breathing, the coughing and gagging sounds. Tossing aside my sheets, I grab my glasses and hurry down the hall in one smooth move. There is a soft glow in the hall to guide my steps on the cold terrazzo floor because Mom keeps the lamp on all night in her room.

We don't need to speak. I can almost put myself in her place and I anticipate her needs. Talking wastes her limited breath and Mom isn't wearing her hearing aide. I work hard to read her body and anticipate her needs. Helping her sit up I *cover her legs with the royal blue cotton lap blanket with the large angel on it. It is time for her breathing treatment, and I'm pleased that we purchased a second machine for the bedroom so Mom wouldn't need to walk to the front* *room. Twisting the cap off the small amber vial, I fill the plastic canister and place the facemask over her head. I try to catch Mom's eyes for a nod signaling that she is ready for me to turn on the machine. She is just too tired, too weak. Her body is drooping, hunched over, precariously balanced on the edge of the bed. Flicking the switch I move to the side of her bed and hold her hand as the treatment begins. Noise from the pump of the oxygen machine and the motor of the nebulizer surrounds us. Half way through the treatment Mom stops to clear her lungs of mucus. When the treatment is completed, I remove the mask again. Mom blows her nose and coughs up mucus into tissues, making gagging noises. Tissue after tissue after tissue is wadded and tossed into the wastebasket sitting next to her bed. It is like she is drowning in mucous.*

Mom shakes her head and looks at me piteously, "This just can't go on much longer. Can it?" My only answer is to squeeze her hand. She whispers, "I guess I'll offer it up to God. But I'm ready to die whenever He calls me." She looks deeply into my face for just a second. Then she coughs again and her shoulders heave forward. Mom clutches tissues to her mouth. Grabbing the plastic bag out of the trash basket I pull the plastic container close to her. Mom's body heaves as she vomits a small amount of clear fluid, slumps back, and gestures for me to help her lay down on the bed. Her hands flutter, our signal for raising the head of her hospital bed. With a cool washcloth I wipe her face, and her eyes thank me. Mom glances at the table beside her bed, and I know she wants a drink of ice water. I hold the glass and the straw because sipping takes all her energy. Every two hours or three hours we repeat the process again. I become more efficient, with a new small basin on her lap. I focus on being efficient because deep inside I am numb with fear, shriveling with feelings of impotence against death, and grieving for things to come. There seems to be no space for sadness now.

The next morning feels brighter, more hopeful. Mom shuffles with hesitant steps to the dining room table after her 6:00 am breathing treatment. "I'm going to say my prayers until the *newspaper is delivered at seven o'clock," she announces the routine I have already come to know so well.*

I'M GOING TO TAKE A SHOWER. WILL YOU BE OKAY FOR FEW MINUTES? I write on her tablet. Taking a shower has become a primal, joyful experience. Goosebumps cover my skin when I undress, then the hot water caresses my body and kneads the stress from my cramped muscles. My clean hair lifts a weight from my mind as well as my body.

I retrieve the newspaper from the front porch and give Mom the city section so she can scan the obituaries. Mom hunches over the newspaper with her magnifier. She calls to me in the kitchen. "Mrs. Mundt died, you knew her daughter, remember her?" I nod with exaggeration since she can't hear anything I say. I point to my ear and she fumbles for the black case to retrieve her hearing aid. By the time I serve breakfast Mom shows me her pill chart, a spreadsheet I made for her to keep track of what she takes each day. "All done 'til ten," she proudly reports. Last week she was too sick to know what pills she needed, or what day it was. So handling her medications is an accomplishment that we both acknowledge.

The day looks different as I sit at the table with my coffee. I NEED TO CALL DR. FRANK AND TELL HIM ABOUT YOUR NAUSEA LAST NIGHT. I'M WORRIED ABOUT YOU; YOUR PILLS MIGHT BE FIGHTING EACH OTHER. I continue, MAYBE HE CAN PRESCRIBE SOMETHING FOR YOUR TUMMY. Mom looks wary.

"Did you call the accountant?" Mom asks.

I pause to think what to write. NOT WHILE YOU WERE IN THE HOSPITAL. YOUR RECOVERY AND COMFORT ARE MY FIRST CONCERNS." I'm exhausted and I feel defensive.

"I want those taxes done as soon as possible. Mom hesitates when she sees my brows knit with a look of frustration and confusion. "If we send in the taxes before I die, you kids won't have any problems with paperwork."

Public Places: How's Your Mom?

Driving across the bridge I wipe away the salty tears creeping surreptitiously from the edges of my eyes, sliding down my cheeks. These tears have been lodged deeply in my tight chest and knotted neck, stored there for months. I keep the emotional gates locked most of the time, not sure when to begin grieving. Tears blur my vision. I admonish myself, "*Don't start now. Think of something else. Prepare for tonight's class discussion.*" I scan the horizon, a vast expanse of blue green water and cloudy light blue sky. My mind wanders as I navigate the heavy traffic. It has been weeks since I have slept more than a few hours at a time each night so I'm prone to spacey intervals. I need a break from care giving, but it is a role that becomes encompassing. Somehow I think the drive across the bridge to campus is a symbolic time and space that can distance me from the illness and dying world. But it seems to cling to me.

Walking toward the mailboxes in the front office I meet Jane, my Family Communication professor, who asks, "How is your Mom?" She stands still, leans toward me and seems to be sincerely interested. The alcove is quiet and deserted. I feel suspended in a far away space.
I take a deep breath and shake my head and respond, "Not too good. Not too good." I don't know how to answer. "This has been a bad week. Her doctor thinks that she will probably need Hospice soon." I pause.

Jane pauses with me and her expression softens and falls a bit. "I'm so sorry. Don't worry about your class work. We can be flexible about deadlines."

I feel overwhelmed by her gentleness and kindness. The word Hospice and all the connotations of impending death flood into my heart as I say the words. Tears are beginning to pool in the corners of my eyes. I nod, “Thanks. I need to run to the restroom before class.” I turn down the hall. I feel confused because I thought I left those emotions at home. I realize that I can use Hospice as a quick way to communicate. The word Hospice lets people know the seriousness of the situation. There is no hope. Mom is not going to get better. She is going to die.

Later standing in the hall I’m waiting for class with several other students. Linda joins me and asks, “How’s your Mom?”

I’ve very aware of the other students waiting. I gulp for a breath and search my mind for an answer. I wonder if I can give her today’s press release sound bite? Should I just use the Hospice story? How do I tell her and all those who ask the story of what is really happening? Is there time for the emotion, physical, medical, and personal layers of the story? Do those who ask really want to know the details? How will it affect them? I look at her and say “Not good,” my throat tightens and I shake my head as I fumble for a tissue. “Sorry I just can’t talk about it anymore or I’m going to start crying.”

Linda doesn’t miss a beat in our conversational rhythm. She says in animated manner, “Oh Elizabeth those earrings are so unusual I just love the three different shades of color!” I realize what she has done and we both laugh which feels good.

“Thanks for the laugh. I needed it. Thanks for understanding.” I reply. I feel a surge of regret or guilt because I believe her concern is sincere, but I’m protecting myself from a flood of emotion I can’t seem to predict or understand. There never seems to be a “right” or place for emotions.

Linda lowers her voice, “You know, I remember my dad’s illness. Mom took care of him for the most part and I ran our family business. It was really hard on all of us, and I was just a kid back then. I wasn't in graduate school but it was still really hard. You have lot on your shoulders. So anyway, take care of yourself. Okay?"

I never knew Linda had experienced something similar. "She is so weak. You know watching a parent die is the hardest thing I've ever done -- you do understand," I murmur. Just then, Professor Carolyn Ellis arrives to unlock the classroom door. During class my mind wanders as I consider what to tell people who ask about my Mom.

At break time from class Carolyn says, "I want to know how your Mom is doing but I'm also concerned about how you are feeling."

My body slumps. I relax a little because I know Carolyn has experienced the loss of her husband to this disease (Final Negotiations by Carolyn Ellis). She understands what happens behind the scenes. "You know how it is with the breathing treatments every three hours and all the mucus. We are up and down all night. Mom doesn't sleep more than an hour or so at a time. I'm getting to be like a zombie due to lack of sleep—just like Annie Lamott's description of caring for her newborn baby in Operating Instructions. She made me laugh and I needed it -- normalized the chaotic situations and feelings somewhat."

Carolyn nods "yes, you get to the point where you actually don't care if you take shower or brush your teeth, you just survive." We both laugh. Then she asks, " What's her oxygen?"

She seems surprised when I answer, "She's on level four."

"That's high, watch for hallucinations and carbon dioxide levels. You can call me if you need to talk." She looks into my eyes as she squeezes my shoulder. "Sorry we can't talk more got to get back to class."

I feel more centered or relaxed as class progresses. It is also a relief to focus on something besides worry about Mom. It is a relief that someone really understands and doesn't think the zombie state is any sort of failure to cope. About half the time I feel like "good" daughter and successful caregiver. Half the time I feel overwhelmed by the uncertainties and chaos.

After class Deb and I walk to the parking lot together. Deb is solicitous but also blunt and to the point, “So pretty rough huh, kid? You look strung out.”

“It’s been a tough time, I feel so helpless – all night long! It’s just so damn hard to see Mom so vulnerable and the body stuff is awful with gagging, choking, gasping. I now know what ‘it breaks my heart’ means.”

“No shit! Its sounds a lot like my asthma only twenty times worse. I panic when I can’t breathe.” Deb gestures in an animated fashion.

“That’s it. Imagine watching your Mother suffer through it over and over and over. I feel wrung out, exhausted in a way I can hardly describe.”

We turn toward our cars to depart, “Yep, the illness narrative is a bitch! You are a trooper, ‘Curly’. Be sure to call me if you need anything, anything, really”. Deb waves. As I start the long drive across the bridge, I feel alone.

Behind the Scene: Feeling Her Pain

“I don’t need to go to a Hospice House. Hospice is for people with cancer and people who are dying.” My Mother says with tight lips and heart. I wait and Mom continues, “I know I’m not going to get better, but you promised I could stay home.”

Now I have a better understanding of her resistance. She must feel so afraid. RIGHT BUT, MOM, HOSPICE IS NOT JUST A PLACE. IT’S A SERVICE. PEOPLE COME TO YOUR HOUSE TO HELP. THEY HAVE A NURSE ON CALL TWENTY-FOUR HOURS A DAY SO WE CAN STAY OUT OF THE EMERGENCY ROOM. DR. FRANK SUGGESTED IT.   This has been another bad week. Last week we started medication to stop the nausea but then the next wave hit.

I hear Mom moaning late in the night. "My back really hurts she gasps. Help me." I'm worried because she has a very high pain tolerance and rarely complains. She can't sit up by herself. I wrap my arms around her shoulders and haul her to sitting position, helping her swing her legs over the edge of the bed. I lightly begin to caress her back as a way of asking her to locate her pain. "Right under my wings, down further, ouch, yes right there!" I can feel the knots in her muscles. Motioning for her to sit still, I hurry to the bathroom and return with sports heating cream that might give some relief. As I smooth the cream on her skin, she flinches and gasps. "I need help to the bathroom," Mom moans and moans. I feel each moan deeply in my own body.

I'm reluctant to pull her arm and the hall is narrow so I get behind Mom and put my arms straight out, under her arms, and we shuffle to bathroom. "This is working good, like a Frankenstein step," I think. Mom needs help lowering herself to the toilet and getting up. I flush for her and we shuffle back to bed. I cradle her body and try to lower her gently to the pillow as she whimpers softly. She grimaces and slumps in pain. My heart feels the pain. "Baby, you are a good daughter. You'll get your reward in heaven for this." Mom continues to moan almost involuntarily. "Tomorrow tell the nurse I need pain killers. I won't live long enough to get addicted anyway." Mom says as she drifts off for another hour of sleep. Throughout the night we are up and down every few hours I try moist heat pads and cream rubs.

In the morning Mom is curled in a fetal position. She seems to stare without seeing and moans. She can't hear her own moans but I think it helps her as she exhales. The home nurse calls the doctor who prescribes medication to keep her comfortable. We decide we definitely need Hospice care. Days later a combination of pain pills and a morphine pain patch seem to change everything. Mom is weak but she announces, "I'm stiff from being in bed. I want to get up for breakfast."

That evening my cousin calls to tell us that my aunt has died. Lillie Margaret was Mom's best friend and her older sister. "Well, she beat me to heaven. I guess we should celebrate because she's with God. You shouldn't be sad." "I thought maybe I would go first. I even thought I was a goner on Sunday."

I WAS WORRIED ABOUT YOU TOO. YOU KNOW I'LL BE HERE FOR YOU MOM WHEN YOUR TIME COMES.

"Did I ever tell you about Florence and her sister? They lived in the same building where LM rented her winter condo. Eventually Flo went to Sarasota with her son and her sister went to Jacksonville near her daughter. They lived to be almost ninet,y but they died within one day of each other."

I felt still and cold.. Was Mom telling me more than Flo's story?

Public Places: Performing Emotions

I'm meeting with Professor Art Bochner to discuss my Social Construction research project, and he asks about Mom. I hesitate and clutch the warmth of my coffee cup. I stare past his shoulder at his wall of books. Then I meet his eyes. I'm touched that he asks but it takes so much energy to find the reply. "Well," I pause, " honestly it was horrible in the last few weeks but today Mom seems better. Maybe it's her new pain pills." I think, '*better than what?'*

"Don't worry about class, we'll work out a schedule. But maybe it's good for you to get a break from intensity of care giving. Of course, I've never done what you're doing but I remember when my mother was diagnosed with Alzheimer's, and I decided to bring her to Florida. It was difficult but I found a very knowledgeable consultant to help me figure out options. If you want her number, let me know."

"I've never done what I'm doing either. I'm not sure what to do most of the time. But you're right, it is a break to attend class, talk with colleagues, and think of ideas not related to illness. I'm struggling to keep up with my classes. I wanted to skip class tonight because I was so tired, and I joked around asking Mom for an excuse note. She refused and was adamant that I shouldn't neglect my studies. It was good for us to laugh about it because I know she feels like a burden."

The phone rings and I nod toward it. "Its Carolyn," Art tells me and then turns back to the phone. "Elizabeth is here. She seems to be doing okay, or at least she's performing being okay." He grins at me. "Yes I'll tell her to call you when we finish."

I call Carolyn and we talk for almost an hour. When I tell her about Mom's pain she suggests that the steroids can cause the pain. I also feel that I can tell her about the constipation and diarrhea. I need to talk to someone who can handle the details of the physical aspects as well as the emotional intensity. But I also try to find the humor in the pain. I tell Carolyn about Mom's habit of giving the doctors and nurses lottery tickets. The especially kind or helpful hospital aides get two tickets for bedpan duty. We laugh and Carolyn says, "You should write about that." We talk about stories from her book, Final Negotiations. The similarities are striking and comforting. I think about writing because I find it difficult to talk about details; maybe writing would be easier.

After class I see Angie in the restroom and she says. "I heard your Mamma might be starting Hospice care." I realize that my classmates share any news about Mom. I wonder if they are afraid to ask me too much. I don't know what to think about that. I tell Angie a little about the week as we wash our hands, but it feels like I'm reciting a news story. "Yes, Hospice will be coming soon. This week her older sister died, her best friend, which depressed her. But most of all I worry about her pain. It hurts me to see Mom in pain. Anyway, I can't talk too long tonight because I must get home by ten for the night shift, my turn to relieve my brother." I feel nervous and frustrated by the time constraints.

Angie's voice reverberates in the restroom, "Ahhhh! You are so good little mama! It's a good thing you're doing! I remember how your Mom sent that cross and holy water to my grandma right before she died. Hey!!! Tell your Mom that I'm going to ask the Virgin to come see her! I'll say a prayer!" Angie remembered how Mom would send prayers to the Virgin Mary to help us with our schoolwork. I think about how Angie's grandmother was about the same age as my Mom.

Cindy meets me as we both approach the elevator. "How is Mom?" She asks.

"I just don't know if I can talk about it. I don't know what story to tell these days. So much happens. Things change constantly." I don't want to brush her off because we are friends, and I also know she is ultra sensitive and cries easily. "I haven't had much sleep. Mom is in so much pain that we are up and down all night. I'm worried and scared. I just love her so much but it's hard. We think Hospice will be coming soon. I'm shaky from exhaustion, fear, and frustration. I'm not sure I can manage my class load this semester." It all begins to pour out.

Cindy touches my arm and I see tears in her eyes. My tears start too. "Mom said she felt sad that she wouldn't see me get my doctorate." I choked. "But I told her that she'd have to help me from heaven." Cindy and I laugh through our tears.

Cindy wipes her eyes and says, "I remember our first class interview together. We talked about our mothers. You said your Mom was plucky and I can see it in your stories about her. Elizabeth, you are plucky just like your Mom. I'm sure that you'll make it."

Conclusion - Reflections

Yelling at Mom

I yelled at my 83-year-old mother while she was sitting in her wheelchair. She couldn't hear my exact words but she saw my angry face and she understood when I threw up my arms and gestured with my hands. I'm ashamed soon after I do it. I'm upset by my lack of sympathy *for Mom's plight. I'm embarrassed that I lost control over such a minor thing. I feel guilty because I grew up in a family where Mom taught us not to argue or express our anger. Mom was always a peacemaker. We had our squabbles as kids but as adults I was the one to 'blow-up' usually during family holiday gatherings.*

I'm lying on the couch when I hear her labored breathing as she futilely tries to pull herself forward in her wheelchair. I groan as I roll over and take a few steps to the dining room. WHERE DO YOU WANT TO GO? I print on her tablet. I shrug my shoulders and flip my palms up in an exasperated way. I don't smile. I roll my eyes.

"I want to get in my pajamas then do a breathing treatment," she replies. She has unbuttoned her blouse already.

BUT WE AGREED THAT I COULD WATCH THE NEWS AND THEN WE WOULD GET READY FOR BED AT 7PM! CAN'T I GET A HALF HOUR TO SIT AFTER DINNER!!!?? WE TALK ABOUT THIS EVERY NIGHT!! I write and mouth the words with angry gestures. The writing even looks angry.

"I can do it myself she says, you watch the news." We both know she can't do it herself. I wheel her into the bedroom and she says, "You finish watching TV and I'll wait here. I know she won't wait, she'll try to do it herself and maybe she'll fall again. I shake my head no, pull out her pajamas and sit on her bed waiting for her to signal she is ready to change her clothes.

After we finish our nightly routine of pajama, potty, and pills, Mom says, I'm sorry I interrupted you. I know you worked all day to have my friends over for the Bridge party. I'm going to buy you a book to say thank you." I almost laughed; the glossing over the problem was so typical of our family. I knew she felt sorry, sorry she couldn't do it herself, sorry she had to ask for help, and sorry I was upset. I felt so petty about watching the news.

I wrote on her tablet, I'M SORRY. I'M JUST TIRED. WE NEED TO WORK TOGETHER ON OUR SCHEDULES. Mom read over my shoulder and nodded. We sat quietly and I tried to think of what to say, how to write it in a short message. REMEMBER WHEN YOU TOOK CARE OF DADDY? SOMETIMES YOU WOULD GET UPSET WITH HIM BECAUSE HE WAS SO DEMANDING. HE WAS FRUSTRATED BY HIS DISABILITY AND YOU TRIED HARD TO HELP HIM WITH HIS PROJECTS AND KEEP THE HOUSEHOLD ORGANIZED.

Mom nodded and patted my arm. "I loved your father but it wasn't easy. You are a good daughter. I don't know what I would do without you. But I get scared when you are mad." Mom took my hand and entwined her fingers in mine. We sat holding hands.

My heart sank in my chest. I thought about how it must feel for Mom to be so helpless, vulnerable, and so dependent after years of vitality. What is it like to say you are 'scared' of your daughter? I never hit or hurt her but she's scared. It's not the first time I've yelled. Who would be taking care of me when I become like her? What was wrong with me? Why couldn't I control my temper?

I had read portrayals of other caregivers' frustrations, exhaustions, and resentments that helped in the short term (Ellis, Edelman, Lamott, Pipher). But I think I had been judging myself by my idealized perception of my Mother's patience. My memory of Mom's struggles with care giving for my Dad opened the door to a new understanding for me. After Dad lost most of his sight, he needed Mom to help him with all his daily tasks, errands, and projects around the house. He was often very impatient. Mom had always been the patient one, but Dad's illness and his needs pushed her to her limit. She would get frustrated and angry. I didn't understand her actions and emotions back then, but now I do. In that moment I felt compassion for myself and perhaps even more compassion for Mom.

Mom taps my leg and motioned to her shoulder –our signal to put arthritis cream on her disintegrating joints. I nod my head and we both smile as I gently rub the warmth into her shoulder and back.

Personal Reflections

This introspective research was an occasion for me to learn more about the social process of emotionality, particularly sympathy, and compassion. I was confused by my reactions. I posed many different explanations. Was it a division of space and time? Was it the result of my existing relationships with different friends? Was I trying to protect others like myself from the harsh realities of illness and death by not talking about it? Was I uncomfortable expressing emotions or afraid I couldn't control my emotions? Was I unsure of how to react because the key question was really about how I was coping, not about my mother's illness? To some extent elements of Candice Clark's process are clear in my narratives: empathy, sympathetic sentiments, and displays of sympathy behavior. I could also see aspects of Clark's ideas on managing a sympathy biography and abiding by rules of sympathy etiquette. Initially I was trying to find answers that were either/or. Was it what others did and said or was it how I acted? Then I realized that I needed to use both/and thinking. Emotions are multifaceted, complex, layered, and often conflicting or ambiguous.

Ellis outlines a "processual nature of emotion" which is accessed through introspection (Ellis, 1991, p.36-37). The process starts with a sense of unreality and then multi-realities, which definitely fit my emotional responses. I also found evidence of the second phase when emotions are juxtaposed, such as my frequent use of laughter and sadness. A key transition is how we protect ourselves from the ambiguity of an emotional moment. In the last stages we want to find others who have been in a similar situation, so we can normalize the experience. I found it so much easier to share my emotions with those who had been in similar circumstances because they knew how it was back stage. Yet in Ellis' final stage we embrace the ambiguity of the multiple realities.

Arthur Frank wrote, “The self is being *formed* in what is told” (p. 55). Through my introspective research I expanded my awareness of sympathy and compassion embedded in other emotions. Through my narratives I developed a new understanding of how I constructed my sense of sympathy and compassion. I focused on receiving compassion, a new experience for me. This is an area of limited study that merits even further research. By looking at others and striving to give sympathy to others, I had neglected to offer compassion to myself. Pema Chödrön defines compassion as starting with self-compassion, “This means allowing ourselves to feel what we feel and not pushing it away. It means accepting every aspect of ourselves, even parts we don’t like” (Chödrön, 1997, p.79). She summarizes the importance of self-compassion, it “doesn’t come from theory, in which we try to imagine what someone else is feeling. It comes from being familiar and so openhearted and so honest about who you are and what you do that you begin to understand humanness…” (Chödrön, 1994, p. 101).

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