

Loving her to the end

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How can I honour my ageing loved one, caring for her with respect and dignity, thereby loving her to the end? This paper is an autoethnography of my experience providing elder care for my mother during the final six years of her life. At the conclusion of this personal narrative, I offer a reflection on the practice of embodied caregiving and perspectivalism, which prompted a transformation in me. The scope encompasses the stages of elder care, from taking on the task to the time of death of the loved one. Adult transformative learning theory informs the paper, as I progress through these steps in learning how to care for my mother. A subtext is that of ascribing great value to the elderly through the means of stepping into their world in embodied caregiving. This process of honouring my mother leads to the goal of loving her to the end.

Keywords: embodied caregiving, dignity, respect, honour, loving, transformation

Honouring the elderly

A colleague* rushes into the faculty workroom frantic, panting and out of breath as we both clamour to find the documents we have sent to the printer. Alas, a paper jam in the photocopier alerts us both to the lack of printouts. He looks at me in desperation, “We’re putting my mother in hospice and I’m flying out tomorrow!” With the explanation he blurts out, I understand his rush and anxiety to get certain clerical and instructional tasks completed in order to prepare for an extended absence which will require a substitute teacher. (*Note: I have changed identifying details of this colleague to protect their privacy.)

I have seen this scenario play out a number of times, only the names, places and a few details differ. What remains the same is the unexpected call, the panic, the rush “to get there in time”. “Getting there in time” could mean arriving at the ageing parent’s side

before they take their last breath, communicating previously unspoken thoughts, or any number of dormant emotions that imminent death brings to the surface.

The trend of longevity encompasses the entire earth these days. The statistics are staggering regarding the multiplying population of those 60 and over. “By 2050, the world’s population of people aged 60 years and older will double (2.1 billion). The number of persons aged 80 years or older is expected to triple between 2020 and 2050 to reach 426 million” (World Health Organization, 2022, Ageing and Health).

As elders live longer, their adult children and perhaps their grandchildren will find themselves in the role of caregivers (Bookman & Kimbrel, 2011). It is this so-called sandwich generation that is taking on the role as care manager or care provider. And it is very often the woman who gets sandwiched in between providing care for her parents while concurrently raising children (or perhaps even grandchildren) and/or endeavouring to rise in professional ranks in the midst of her career. The woman’s personal life concerns may get squeezed (or sandwiched) in between her focus on childcare in early adulthood and elder care in later adulthood (Roszak, 1998/2000). It has been the case for decades that the majority of elder care work falls on the shoulders of women; there has been little change over the years. “The fact that the responsibility for caring is still ascribed on the basis of gender has not been taken seriously into account” (Wærness, 1987, p. 134). For these reasons and more, many adults will unexpectedly become caregivers or care managers of their elderly parents, and the more knowledge they can obtain, the better and smoother will be their journey.

As noted, caregivers contribute major amounts of time and energy to their role, and it inevitably causes stress. Analysing and writing about this role can be a therapeutic act of reflection. (Gloviczki, n.d.). Writing my story will no doubt prove to be cathartic and healing as I reflect on the years of taking responsibility for my mother’s care (Ellis, Adams & Bochner, 2011). Caregivers will likely connect to my experience, as this may very well be their own reality, and they can see themselves and their elderly loved ones in the scenario (Ellis, et al., 2011).

Therefore, with the stress, lack of preparation, plus many unknown variables about caregiving, how can I honour and care for an ageing loved one, ensuring that I love her to the end? Many will ask this, as longevity increases and the sandwich generation gets wedged between elderly loved ones on one side and career and/or children on the

other. What unfolds here is an autoethnographic narrative, a true account of my foray into the elder care world with a concluding reflection on how I learned to honour my mother and in the process, experienced my own transformation. Now I invite you to join me on this journey.

Honouring her (Mom) as the journey begins

I stand in a waiting area and gaze out the window of an office building in the heart of my hometown in silent meditation. Mom and I are at the law office where my parents drew up all their end-of-life legal paperwork when my father was still alive. Now here we are again, years later with the same attorney who is familiar with our family situation. My mother, her attorney and the attorney's assistant are questioning my mother privately in the conference room away from my hearing. Minutes pass, and more minutes. Finally, the conference door opens, the sound breaking my reverie.

They beckon me to join them inside. "Your mother says she should have done this a long time ago," the attorney's assistant tells me as we re-settle in the law office conference room. What she is referring to is the legal transaction that she will now formalize: that of my mother making me her sole Power of Attorney, thus giving me charge of all of her financial, legal and healthcare affairs. Thus begins a six-year journey (until her passing) of managing, providing and overseeing my mother's care and all of her affairs, both up close and from afar. The tumultuous tug-of-war ends, as it has been a battle, a familial conflict over who will take charge of Mom, now that she needs more help. Mom emerges as victor. Mom has found her voice and not only that, but she now also has agency, making the life changing decision to move across the state back to the place she has spent much of her childhood. She will live close to many loved ones, spending the last years of her life surrounded by caring relatives, one of the most important decisions of her life.

This is the true story of my mother ("Mom") and me during the final six years of her life. I have chosen to share it partly as a healing process, but also, and perhaps more importantly, to impart comfort and courage to those who find themselves in the caregiver role. The narrative includes mistakes I make and offers altruistic methods of treating the aged with the respect and dignity they deserve. Perhaps the reader will find insights for giving their aged loved one a farewell with honour, as the goal is to love

them to the end. (This account is factual; I have changed only the names and identifying details of others to protect their privacy.)

Honouring her with decisions

It is time to move Mom into an assisted living facility. Because she has chosen to move across state to live close to relatives, I decide first to investigate several places in that geographical area online. I choose six facilities and a cousin and I visit them in person when I am in town. Out of these six, I narrow the selection down to two, and place a security deposit at each one, ensuring that Mom will have a reserved place, if she chooses to live there. Then I take her to these two facilities and let her tour both assisted living homes. We visit the first one and she looks around without much comment. Then we go to the second, she walks into the vacant apartment, one of the two largest in the facility, looks around and remarks, "Yes, I could live here!" It is a perfect fit, and I am pleased with her decision. I am thankful that I have honoured her with the decision making process for her new residence.

Later as the dementia advances, I cannot depend on my mother to reason or think logically. I learn that I have to think of the roles of parent and child in reverse. I *become* the parent and she is the child; I must accept the role as *parent* and act accordingly. Recognizing this has taken the angst out of difficult decisions.

Honouring her with dignity

Weeks after she has chosen the assisted living facility, I am checking my mother in to her new home. The assistant director and I sit at a table, discussing options and signing papers for the details and direction of Mom's care, such as dietary needs, medicines, as well as the options available to the residents such as shopping trips, social time, and exercise.

"Will you want your mom to have hair appointments? The stylist comes once a week," the assistant director inquires. "Yes, I agree to this," I nod my consent. "Good," she says, and explains, "Some family members don't think it's important anymore for their loved one to get their hair done, as there is no need to look nice." In other words, *why would Mom need to look attractive?*

Well, I can attest to the fact that my mother does not walk, shuffle or creep, but rather she sashays down the corridor each week after getting her hair done. I learn how much this seemingly small practice honours her with the dignity of grooming and the sense of pride in her appearance.

Honouring her for her birthday

Cake, candles, fun galore, Hilda's turning 84! Thus reads the invitation on the card I design to send to family and friends for Mom's birthday party. She is now in her fifth year of assisted living residence and I know her faculties are declining; I want to give her a party while she can still enjoy it. Two of my teenaged cousins come early to decorate the party room at the facility. It is a fun occasion and relatives come from near and far. Now, hours later, the party is over and family and friends have gone home. After this evening of fun, frivolity and lots of love, what remains are a few pieces of cake in the bakery box and opened gifts on the table. Only my cousin Joy and I stay, cleaning up the cake, snacks and drinks, taking down the party decorations to return the room to its usual state. My mother is sitting nearby and watching. Along comes a facility caregiver who starts up a conversation with Mom.

“How was your party, Hilda? Did you have fun?” “Party, what party?” asks Mom, sounding confused as Joy and I look at each other in exasperation, thinking of all the work we put into it. “Don't you remember?” we say, “All the people here, your grandson came from out of town, all your local relatives, we sang, and ate this bakery cake...” “Oh yeah, yeah, now I remember. Yes, it was nice, thank you,” my mother finally concedes. Joy and I sigh in relief and return to our work, removing all signs of this event, this party for an eighty-four-year-old who might not remember it at all the next day. Even if she does not remember, I do, and that is what matters. I know that I have done what I can to honour her and to make her feel special. “And we had fun, yes, we had fun,” I add.

Honouring her with hellos and goodbyes

I arrive into town, make my way to Mom's assisted living facility and saunter into the dining room, where she is happily enjoying mealtime with other residents. “Hi, Mom!” I

call out and she begins to cry, tears of joy, as she recognizes my voice. However, at times we also experience tearful farewells.

After one visit of spending weeks with Mom in her apartment at the facility, I leave to make my way back home (miles away in a different state). Soon after I have bid my mother farewell, one of the facility employees finds Mom lying in bed curled up in foetal position, sobbing because she misses me. However, this facility caregiver wisely makes Mom get up out of bed and refresh herself. Then she coaxes her to walk down the corridor to join other residents in the parlour to socialize. Soon this daughter's departure is a faint and distant memory and Mom is happy once again amongst friends in her home! I recognize that she has her own life to live, and honouring her means learning to leave her in the midst of family or friends as I depart the scene silently.

Honouring her memories

Mom sits at her dining room table at the nursing home, talking about how she is looking forward to my father coming to see her that very day. My parents had been married almost 54 years when my father died, and he had been gone over six years at this point. Oh, how happy she is going to be when she sees him! She wonders how soon he will leave work and get here. Yet I make the mistake of bringing my mother the bad news:

“Mom, you know Dad died years ago; he won't be coming to see you!” And with that she bursts into tears. What a mistake on my part. I have misjudged; I hurt her feelings. I railroad right over her emotions, her words, her hopes and dreams... And then I remember: age does not remove humanity. Age, even dementia, does not erase the memory of all loved ones. Lesson learned! I decide next time to honour the sweet memories of her cherished loved ones and allow her to *live in the past*. Yes, I repent; I start over, and learn to honour her memories.

Dishonouring her: My shame and regret

Truly, not every interaction with Mom will win me Daughter of the Year award. There are times I underestimate her judgment, her ability to make decisions or I dismiss her desires, not listening to her needs. I must also mention those couple of times when I am slightly ashamed of her in public, as when she is still independent but not grooming herself as well as she used to, giving her a dishevelled, unkempt look. Oh, how I would

like to do these moments with her over again, offering her the respect and dignity she deserves.

Honouring her with listening

Mom amazes with wisdom and insight mere months before her death. One day I sit with her outside in the courtyard of the nursing home to ask her advice on three important areas of my life. I am contemplating changes and decide to seek my mother's input. To my astonishment and delight, my mother, (although suffering with advanced dementia and in the final months of her life), gives me excellent advice. She sits in her wheelchair, diminutive and slightly hunched over, yet speaking clearly and eloquently. It seems as though a door has opened and a younger, mentally alert person has stepped onto the scene. This is a unique and pleasant memory in which the roles have momentarily reversed and her intellect shines brightly. I may have honoured her by seeking input into my decisions and choosing to listen, but she has honoured me by giving me motherly advice.

Honouring her with inclusion

Hospice workers and healthcare personnel claim that the sense of hearing is the last to go. There are times when Mom is sitting quietly amongst family and friends in the midst of a gathering, appearing to be fast asleep or at least not aware of her surroundings. She is usually unable to keep up with the conversation and unfortunately, that means we exclude her. Yet, although not very talkative, at key points, she speaks up and lets us know that she is actually right here with us, following the conversation and able to join in. In fact, at one cousin's birthday party, well after the dinner is over and many of the guests have gone home, the hostess decides to offer another round of birthday cake. To my cousin's question, "Who wants dessert? Is anyone ready for more birthday cake?" my mother surprises everyone by *waking up* and being the first to respond, "Yes, I will take a piece of cake!" She gives us all a good laugh. I realise I must honour her by including her in all conversations.

Honouring her at her death

It has been my desire all along to be present at my mother's passing. I want to be at her side as she passes, not only for her care and comfort, but I want it for myself; I choose to

experience the reality of death of a loved one up close, since I have not been present at the passing of other family members.

It is a Friday morning before my work begins as a college professor. The nursing home calls. The nurse tells me the end could be near, today, tomorrow, next week. They will call hospice. Over the previous few months, I have intended to pack a suitcase to have it ready for this moment, but alas, I have repeatedly postponed that task. Now I must pack hurriedly and it is not for some future moment; the time is now.

I quickly make arrangements for my teaching responsibilities, call the airlines to book a flight, reserve a seat on the airport shuttle, drive home and ask a neighbour (through my tears) to take care of my dog while I'm away, pack a suitcase, leave, take the shuttle, get on the flight, etc., etc. Just a few hours later, I find myself at my mother's side in the nursing home, three states away from where I had been in the morning.

I make it. She lasts for another week, and I am so thankful for the privilege of spending these final days of her life with her. I am there at the moment Mom dies, and I call it both beautiful and terrifying. Beautiful, because I know that she is at peace. Terrifying, because it is a strange and ugly thing to pass from here to there in an instant, and everything physical about the person changes: her face, her colouring, her expression. Mom has left her body; she is no longer present.

Finally, in closing my own journey of elder care, I express gratitude for the precious and rich memories of time spent with my mother, especially those final years. I have achieved my goal of loving her to the end. Returning to my opening paragraph, does my colleague make it to his mother's side in time? Yes, he does, and he too is able to say things to her that he has wanted to say and make it a meaningful farewell.

Discussion on how to give honour: A Reflection

How can I honour my ageing loved one, caring for her with respect and dignity, thereby loving her to the end? My mother has died; my caregiving role has ended. In this section I reflect on the practice of embodied caregiving, the concept of perspectivalism and the transformation in me that they engendered.

A Reflection on embodied caregiving

In the autoethnographic narrative I combined the typical methods of ordering, which are 1) narrative time order as events happened chronologically or 2) arranged by topic or theme (Tyner-Mullings, 2022). What was key here in this autoethnographic account of elder care was for the senses to be engaged in providing hands-on care giving. In my case, being present with my mother was not always possible, as we lived in different states, and she had chosen well and wisely her place of residence. Therefore, my experience of being with her around the clock was priceless, as I moved into her assisted living apartment for weeks at a time during my visits and I could see her life on a 24/7 basis. Thus, her residential facility and the residents formed the framework of my observations, and the physical surroundings day in and day out informed my research, making me not merely a visitor, but a participant in the elder care life and a resident researcher (Adams, Ellis & Holman Jones, 2017).

I call this embodied caregiving, a term I derived from “embodied writing” (Ellis & Bochner, 2000, p. 734). Furthermore, it benefited both me and my mother, the young and the old. The interaction amongst people whose ages span across the spectrum improves their health in multiple aspects (Cockrell, 2022). Furthermore, this foray into the elder care world revealed my initial ignorance about the elderly and their needs (Holdrege, 2007).

Therefore, as I entered the world of residential elder care and gave my mother embodied care giving, I experienced a transformation. There was value to this approach, that is, learning to live (albeit temporarily in my case) in the world of wheelchairs, blandly prepared meals, schedules run with announcement reminders on the loudspeakers and folks shuffling their feet down the hallways. These ageing residents leaned onto the wall as they shuffled along to make room for the nurses and their assistants, as these health care workers wheeled the medicine carts up and down the corridors dispensing pills. At times I wondered whether it was true longevity or modern medicine keeping the residents alive. Yet all of these observations provided a view of the world from the perspective of my elderly loved one, my mother. In other public settings, I became aware of wheelchair ramps, or the lack thereof, in treacherous places such as parking lots, sidewalks, stores, restaurant entrances, and even toilets. This practice of personal hands-on caregiving enabled me to recognize the many difficulties that the disabled and elderly deal with daily

(Holdrege, 2007). This practice also helped me, the care provider, become less selfish, enabling me to understand and enter the psyche of the aged (Stevns, 2021).

A Reflection on perspectivalism

A subtext has been the growing understanding of how to value, or honour, the elderly as human beings worthy of our time, talent and treasure, and validating their voiced desires and needs. In my case, the concept of perspectivalism pushed me into this realm. Perspectivalism, put simply, is learning to see through the lens of another (Frame, 2012). It enables us to view the world from a different perspective, allowing for a better understanding of the other's challenges. Through this lens, I began to see my mother as a person with desires, disappointments, hopes and heartaches, in other words, I realised she had human vulnerability common to all. Heretofore I had thought of my mother as just an old person with physical needs, ignoring the emotional. After learning to listen to her, really listen, as one caring human being to another, I became aware of her as a whole person not unlike myself.

In fact, I learned something valuable about my own mother from one of the facility nursing assistants. It was this employee's job to wake up the residents and get them ready for breakfast. She happily proclaimed that she would come to my mother's room and wake her up first because Mom always woke up with a positive outlook and say something funny that would put this assistant in a good mood for the rest of her workday. This helped me see my mother in a new light, as entering her world changed my perspective. Seeing my mother this way fostered my compassion, which would not have occurred had I not been spending weeks living in her world, her apartment, observing her and her everyday challenges, living amongst other ageing residents.

A Reflection on transformation

Throughout the six-year span of time that I took responsibility for the provision and management of care for my mother, I made many mistakes, celebrated many successes, and met with many professionals in the healthcare industry, the financial world and the legal profession. I progressed, regressed, and ultimately made my way through the phases of adult transformative learning (how an adult changes their perspective due to wrestling with new information), indicating that I had shifted my thinking and thus my behaviour

in the presence of the elderly. The adult transformative learning process begins with a disorienting dilemma, then proceeds through these phases: self-examination, critical assessment, recognition of shared experiences, exploring options for new behaviour, planning a course of action, acquisition of knowledge, trying new roles, building confidence, and reintegration (Stover & Lahman, 2021, pp. 2-3). The process takes willing adult learners through critical self-awareness and exploration of new options. The learning ends with the final stage of reintegration, in which adults can open up and tell what they have learned in order to assist others through the process (Stover & Lahman, 2021).

Thus, it was through embodied caregiving and changing my perspective that I learned to appreciate Mom's humanity. I began to understand that even in her advanced age, she experienced the range of emotions, as she was human too and I delighted in getting to know her in a fresh, new way. This was my transformation.

Mom's frailty was physical, her body and mind deteriorating due to age and disease. Yet inside lived a woman of fortitude who exhibited emotional strength. The portrait of her and my father which I proudly displayed in her living quarters symbolized days gone by, including that of keeping a strong marriage which lasted over fifty years, successfully raising four children and managing a strong, intact household. I watched my mother thrive on the attention she received at her first assisted living facility. She took on the name "Party Girl" and even claimed to have a boyfriend.

I therefore decided to find out the key to my mother's newfound contentment and satisfaction in life as I watched her flourish in her new home. She had suffered hard losses, three of her family members (her husband, son and youngest daughter) having died within a three-year span of time. And she acknowledged her pain and willingly shared her personal losses when she made a new friend. So, how was she enjoying life in the midst of all this pain? How had she managed this dynamic do-over? I dared to ask her one day.

"How are you managing to go forward in life, Mom, after all you have been through?"

After a moment, she very thoughtfully responded, "I knew I could curl up into a ball and die, or I could decide to keep going and wade through it." Wade through it, indeed. Moreover, she did so with gusto. Her verbiage indicated significant resolve. She had said she would wade through it, not merely walk or stroll through it. Wading is much

more challenging; it requires more effort. My mother's word choice indicated her profound awareness of her pain and the obstacles she had to overcome in order to choose life after such loss. In doing so, she left a meaningful legacy to follow.

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