

REFLECTIONS ON CAREGIVING: BURDEN AS GIFT

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This narrative offers reflections on both the burden and the gift that caregiving is, and chronicles the author's attempts to embrace the felt burdens while still celebrating the time with her mother during her last years.

"Life is such a miracle, and a lot of the time we feel only resentment about how it's all working out for us." (Chodron, 1991, p.29)

My mother and father grew up in Englewood, Colorado where, in their mid thirties, they married, raised my brother and me, worked, then eventually died. During their working years, my mother was a secretary at a community mental health center and my father was a hairdresser and liberal politician. My father died shortly after retiring in 1978, Mother, a year ago. She was almost 90, having lived in her own apartment in a retirement community she and lifelong friends helped to create until one month before her death.

The following reflections chronicle my journey of providing care for my mother during the last several years of her life. My intentions in sharing this personal journey are several: first, that you, the reader, will be able to embrace the gifts caregiving affords while your loved ones are still alive. Some of these include gifts of intimacy, loving freely, and having another's life placed squarely in your care. Second, I hope that the personal accounts further dialogue about the often-gendered equity arrangements in families and society. And last, I wish to honor my mother by way of these reflections on the often awful, and yet wondrous, job caregiving is.

I am presently a university professor and very part-time social worker in private practice. The following reflections were written over a five-year span, the earlier ones occurring while I was still a doctoral student. After 25 years of practice as a school social worker and family therapist, I decided to get my Ph.D. At about the same time, my mother was diagnosed with "a mild case" of Alzheimer's disease. In her case, the disease took the form of acute short-term memory loss. My doctoral work focused on Gender Issues in Couples Work. Since then, my research centers on addressing power, privilege and oppression in families (Parker, 1997 & 1998a, 1998b). The reflections here, in a sense, chronicle the tension between my professional quest for equity and my more private realities. While this writing expresses issues of loss, the theme I want to highlight is caregiving, a theme often missing in grief and loss literature but important in the realm of equity.

The journaling entries I share with you, written during my mother's decline and death, express mostly the burdens of caregiving. As readers know from the vast literature on caregiving, it is not an easy or problem-free job (Hooyman & Gonyea, 1995). When immersed in the burdens of the job, the gifts are often obscured—the gifts that I am so acutely aware of now that she is gone. Moreover, the second class status afforded

caregivers renders the task less socially desirable. It is the “grunt work.” Care for children, the disabled, and elders remain primarily women’s work (Hooyman & Gonyea, 1995; Lee, Dwyer & Coward, 1993; Sollo, Wolf, & Agree, 1990, Zimmerman & Addison, 1997). Certainly, Mother’s day-to-day routines and back-up care fell to me as the in-town daughter. As a feminist researcher, I was acutely aware of the inequities in the division of labor between my brother and me. This awareness was a mixed blessing. It provided ready first-hand experience-based evidence and perhaps fueled assertive requests for assistance. Yet, I am aware now that it also served to fuel my feelings of resentment, which, though understandable, I now regret.



“Grunt work,” while socially disavowed, is viewed from other perspectives as optimum fertilizer for spiritual practice (e.g., Beck, 1989; Chodron, 1997). There is ample, even rich, opportunity in “grunt work’s” boring repetitiveness to open again and again to the present moment whatever it holds. It was in this spirit that I wrote the following journal entries. Journaling was, for me, a way to stay present with the angst and grief that can accompany caregiving, even for my beloved mother. For that reason, these writings mostly do not reflect the joyful moments, which are for all of us much more comfortable to inhabit. Readers should be aware that caregivers in their despairing moments mostly do not feel up to the job (Lustbader & Hooyman, 1994). Certainly I often did not.

The first reflection is one I share cautiously with readers. Please know up front that my

brother was a very good “absent caregiver”—always acknowledging of my in-town and thus far more full-time caregiving status (e.g., with words, very generous gifts, and several long-stay visits at crucial times in Mother’s care as well as many short-term intensive visits). I remind you that these writings are MY reflections, a process I used to work with my situation. They therefore do not reflect THE truth about anything, rather my “truth” in the moment, a “truth” I hoped would become clearer and therefore less TRUE (i.e., solid, un-movable, unnerving) in the writing. As the postmodernists remind us, truth is made not found, and it is multiple (Anderson, 1995, Rorty, 1989). Writing was intended to help me learn to take myself less seriously, not more.

*Our life’s work is to use what
we have been given to wake up*
(Chodron, 1991. p. 30)

Reflections: January 1995

My brother and I were having dinner after my arrival to visit him in Seattle. In the course of our catching-up with one another, he shared some of his thoughts about taking a sabbatical (he is a university professor): Should he take one? If so, when? He was describing some of the alternatives that came to mind for him if he decided to take one: A month in Japan? A three-month meditation course? Stay at home and focus on writing projects? As he shared these options, I waited for some mention of our elderly mother and her care. I listened for a plan to come to Denver to relieve me, or to help with her care for a few months or even weeks. Having never left our hometown, I inherited her caregiving. Moreover, being female, and perhaps being the oldest child, the position of caregiver was socially transmitted early on. As I now finish my Ph.D., leaving town to assume a faculty position is out of the question. Even a weekend away to see my brother or friends

is difficult in making arrangements for her care. The disproportionate responsibility I carry for our mother's care limits my options personally and professionally.

I sat there rather stunned, thinking, "Do I bring this up and ruin our dinner—since naming power issues never feels good? (Goodrich, Hare-Mustin, & Rampage, 1994). Do I remain silent, make lighthearted conversation, and leave this current version of our power disparity unnamed? This seemed impossible. After all, this is my research—this very dilemma: the difficulty of raising power inequities, especially with the person who holds more social privilege in relationships.

I did find a way to raise the issue. I said, "I would like to find a way to write about this: that you can contemplate a sabbatical, and the entire world is a possibility for you. The thought of spending more time with mother, to give me some extended time off, does not seem part of the picture."

So, we talked about this. He thought I raised the issue well ("I'd like to find a way to write about this"). He is always especially interested in my writing projects. And, nothing has changed. We can talk honestly. He appreciates the burden I carry. He has been very generous in supporting my dissertation research with free airplane travel to research interviews and other lavish gifts to acknowledge the uneven responsibility I carry. But the burden remains mine. What does help is *help*. And, that is mostly not available.

And so, we talk; I write; and I am still in charge. The inequality is raised for conversation. The conversation does not feel good. And the roles and duties remain mostly the same.

In this next writing Mother's short-term memory was worsening. However, because her long-term memory was intact,

she was still able to do some things on her own when I telephoned her many times with clear instructions and reminders before an event.

October 1995: She made it!

Mother says, "Do you mean I have to go [to the doctor] all by myself?"

Spent last night awake, tight chest,

Worried about mom.

Worried about her rash.

Worried about her mortality.

Worried that she will die.

Worried that she will outlive her mind.

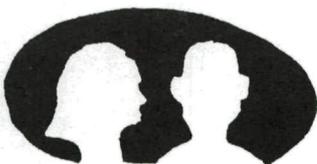
This morning, up early to add consent forms to the other dissertation letters that I need to mail this morning.

I arranged for a doctor's appointment for Mom. A van was to pick her up and take her. I called her to tell her so. She called me right back confused about the details. I ask myself, "Can she get there on her own?" She is scared, confused, and child-like. I have a full caseload today, plus dissertation requiring my time and energy.

I do not want this caretaker role today. And yet, I have it. I wish I could own it more goodheartedly—do my "martyred woman" role cheerfully. I feel guilty for wanting my own life, my own time, what I believe my brother has.

Because of telephone calls (to doctor, to Mom's retirement residence, to Mom) there is now no time for exercise class. So, I sit down with tea and journal. I am not going to leave my mother (to pursue a job, education, fun). I cannot leave my mother. In my fabric is the obligation and desire to care. Leaving has never been a choice.

Later, Mother went downstairs on time to catch the van that I had arranged, at 1:30 p.m. She was told it left a half-hour ago at 1:00. When I called the receptionist to make sure Mother was downstairs waiting on time, I was told curtly the same thing. When I



reminded the woman that she (the same receptionist) had told me that the van would take Mother at 1:30, she backpeddled, and then reluctantly said, "I'm sorry; I was mistaken." She informed me that Mom had taken off walking to her appointment. It was about four blocks away. Fear filled me—guilt at putting my needs (e.g., exercise, journaling) before taking her myself. I had visions of her never making it to the doctor.

More telephone calls to get the van driver to go look for her, then to her doctor's office to see if she made it. She arrived!

The doctor's receptionist promised to call the van to pick her up when she was finished. They didn't! Mom walked, again. Though failing in memory, somehow she made it. My Mom is amazing. I am a wreck!

June 1998

Last night at her (our) favorite Mexican restaurant, Mother kept comparing my small arm size to one of an obese woman nearby. I was worried that the woman or her son could hear my mother's comments and would feel bad. Mother, acutely in present time, was simply amazed at the woman's enormous size, and was exclaiming so—over and over and over again in each new moment where the observation, for her, was fresh.

I felt irritated. Though I *knew* she could not help it, I wished for her to be able to be her old more considerate self. I wished too for her to be able again to converse with me.

Why can't I be patient, compassionate, and treasure the time that I have with her as her life nears its end?

Why can't I accept and love her just as she is now?

Why can't I accept my job as caregiver, versus resist it and feel angry with her, then hate myself for being angry?

This next reflection occurred after I had been appointed assistant professor,

fortunately, in the town where she and I already lived.

June 1998

Today at lunch, Mother was hunched down over her plate. Her head was down and she seemed far away. Yet, when I asked what she was thinking, she replied, "I was thinking about how proud I am that you are a professor." I had just been to graduation and had told her about it, but had no idea she was able to grasp what I had said or that she could remember the conversation. In the moment, Mother is very lucid and sometimes surprisingly remembers.

I was often harried managing her life and care along with my own. Many times I arrived at Mom's and went right into gear—washing dishes, cleaning up her apartment (since she was now forgetting to do so herself), cleaning up "accidents" due to her increasing incontinence, and otherwise trying to manage things so that she looked more capable to her retirement community than she actually was. I knew that if the management knew how frail she was getting, they would insist she be moved to nursing level care. This new location would be unfamiliar to her and therefore confusing. I was worried that it would unravel her fragile hold on competence. As well, she would not be able to take her dearly loved cat companion with her. Consequently, I endeavored to keep her independent as long as possible. Her current arrangement (an independent apartment in a tiered retirement community) was lodged in her long-term memory and afforded the independence she relished. She amazingly continued to manage going to the in-house restaurant for meals, and she still had lifelong friends and neighbors living in the same community whom she met for dinner every evening.



August 1999

The supervising nurse at Mother's retirement center called this morning. Mom's confusion is worsening.

I feel sad.

Hoped I could prevent the worsening—that Mom could die in her apartment, as she so much wanted and be spared having to go to a higher level of care, losing her cherished independence.

I am so afraid for her.

How will she experience these last years of her life?

What will it mean for my life now?

I am terrified of growing old myself. I will not have a "me" to care for and manage me.

This is such a difficult job—such a great responsibility—another's life, my mother's, in my inadequate hands.

I feel anxious, scared, and sad.

November 1999

This day I brought in lunch for Mother and me. As I sat with her, I was struggling to BE with her and also to be present with all that I was feeling.

Eating with Mom

Eating with Mom.

Silence.

Her eating requires all her focus.

Coordination is slipping.

Mind focused only on the present moment,

I work with myself.

Breathe.

Be with irritation, boredom, and sadness.

This is my mother at 89.

Grunting.

Her mantra, "Like so," repeated over and over.

Does it give her comfort?

She can't tell me because she can't remember she has just uttered it.

Being with her.

Being with me being with her.

I want to feel only compassion and love.

I feel so much more.

Breathe.

Thanksgiving 1999

My brother said, "I've been exhilarated all day! We're doing a counter-culture Thanksgiving. Are you?"

I think, "In your dreams. Have you forgotten I have the Mom-care job? You get to be the free, good son. Me, the wretched daughter!"

I say, "No, we're still doing a traditional one with the Mom-care job."

Now I hate myself for having complained. He hung up fast when I said what I did. A burdened sister is a bummer to a counter-culture day.

I wish I were better.

I have little time left with my mother.

I want to savor it,

Yet, it is so hard.

I am judgmental

Or

I complain.

Then I am full of regret.

I wish I were better.

December 1999

Mom:

Sparkling blue eyes.

The kindest person alive.

My mother has been the best Mother.

All loving.

Ever giving.

Bright, independent woman tenaciously fights for her quiet dignity.

Heavy heart.

How do I shed the expectation, the judgment, the yearning for my mother whole.

She's there in moments.

Eyes bright.

Profound wisdom.

Gentle love.

We connect.

I want to be the all-loving, protective space for my mother that she has been (is) for me.

I fail regularly and miserably.

In March, Mother's health had deteriorated sufficiently that we needed to move her from her independent living apartment to a skilled nursing room. Though her short-term memory was almost gone, her long-term memory allowed her to be somewhat independent until the last month of her life. At this point her longtime friends who lived in the same retirement community were concerned that she needed more care. The retirement community manager required the move. Reluctantly, I acquiesced, knowing Mother would not understand the move and that it would take away that for which she so courageously fought: her independence and life with her cat, Chally. On the nursing care floor, she deteriorated rapidly, dying one month later. In a moment of clarity she said to me, "I think I'm giving up."

March, 2000

My Mother:

Safe

All knowing

Always there for me

She's dying.

My mother

Full of light and always love,

Your sparkle has gone.

You ask to go home.

"Take me home."

I'm dismantling her home.

She says, "Will I ever go home?"

My mother is dying.

When I'm scared, she's always there –

"Face the wall and your nightmares will go away."

Letters every day intended to help me feel

less homesick when I went an hour and a half away from home to college.

A sewing machine to take with me to college to occupy scary thoughts and to focus my wild mind.

The call from her to say, "Daddy died."

Lunches with Mom every Saturday. She's willing to do whatever I want to do, just pleased to be with me, anything but self-centered.

What will I do without you Mother?

I am so scared.

"You are such a sweet daughter"

Mom says as I paint her nails today.

I worry that I have rendered my mother homeless, in the move from her apartment to the skilled nursing floor.

Another day, in Mom's last week, she says:

"I love you so much. You are my dear, dear daughter. I am so proud of you."

"Mother, I love you so very much (more than you'll ever know).

You are my dear, dear Mother.

I am so proud of you."

Written in Mother's first then last week on the skilled nursing floor.

Mother died with all of us there with her: my brother, our partners, and me. We knew she needed to die. Her body had given out, and she had been clear with us that she did not want to live beyond her ability to be independent. I realize now, months later, that context is everything. In this moment, knowing the finality of death, I would give anything to have my caregiving job back—to have Mother alive and with me again. My complaints occurred within the context of



Mother not dead. Though the complaints were (are) legitimate—caregiving does fall mostly and unfairly to women (Hooyman & Gonyea, 1995)—after her death they seem unimportant compared to the loss. As I said in the beginning, women both get to care and they *have* to. And, the “have to” unfortunately can serve to obscure the gifts and intimacy caregiving affords. I think this was especially true for me as a feminist whose cause is equity. Worse than that, the burden of the job, caregiving, can steal from appreciating the precious limited time we have with those we love and for whom we care. What helps is help—someone with whom to share the work. Yet, recent research on caregiving suggests that equity between the genders is still remote. Family life as is typically practiced in our society is not just, or equitable, for women across racial, class, and ethnic boundaries (Berardo, Shehan & Leslie, 1987; Blair & Lichter, 1991; Dominelli & McLeod, 1989; Hochschild, 1989; Hooyman & Gonyea, 1995; Okin, 1989; Rabin, 1994; Thompson & Walker, 1989; Zimmerman & Addison, 1997). This inequitable division of labor occurs not only in the interior of family life (e.g., housework, child, and elder care), but also in exterior contacts with the community. Accommodations that women make in their work life to care for others perpetuate women’s economic disadvantage relative to men for life (Friedman & Greenhaus, 2000; Ward, Dale, & Joshi, 1996; Williams, 2000). For most men, caregiving still resides as a choice when their more important work or life is not calling them (Carter & Peters, 1996; Rabin, 1996; Zimmerman & Addison, 1997).

Moreover, entrenched American norms are problematic. First is the market world’s notion of the “ideal worker” (Williams, 2000, p.1)—someone who is now expected to work full-time and overtime and take little or no time off for childbearing or people care. And, second is the almost unquestioned norm

of “domesticity” (p.1), whereby caregiving is mostly assigned to marginalized caregivers (mostly women), who are therefore cut off from many social roles and employment opportunities that offer responsibility, authority, and good wages. The work world continues to be structured around the assumption that ideal workers have access to a flow of family work, thus perpetuating the economic vulnerability of caregivers (Williams, 2000).

I am left with many questions: How do we right the inequity dealt women who will continue to carry major responsibility for the care of children, elders, and homes? How do we recognize the inequity without becoming victims—the wronged, oppressed ones, who resent their job? Does the sharing of the burdens (actual help) free up appreciation for the wondrous job that caregiving can be? How do we interest those not socially assigned to the job (i.e., mostly men) to willingly be aware of and assume their fair share of responsibility? How do we change the work force and social norms that elevate the “ideal worker” and marginalize both paid and unpaid caregivers and service workers? And last, how do we love fully—our families, intimates, friends, and communities—each moment of our (and their) precious lives?

Reflection on Reflections

This experience is a difficult one to write about without sounding like a whiner to myself, or an ungrateful, selfish daughter. Yet, I believe other full-time caregivers who both appreciate the gift in the job and resent the inequitable assignment must share some of these sentiments. There is intimacy available in doing-for-another—doing those private, intimate, mundane (but necessary) duties day to day. Yet, I worry there was a loss in my ability to fully appreciate my limited time with her, or to care for her with the grace and full-out unselfish willingness she so deserved. She was that kind of Mother to me, after all.

What can I suggest out of this experience?

I come back to the notion that help helps. And in order for primary caregivers to get help, change is needed on the personal, social, and political levels. First, on a practice level, social workers and family therapists must focus therapeutically on the process of unraveling issues of privilege, power, and oppression in the issues clients present. Treatment focus needs to be broadened from emotional and interpersonal dimensions of clients' lives to also uncover socially mandated hierarchies of power. For example, workers can inquire into the consequences (both positive and negative) of the way relationships are organized and decisions are made. What are the consequences (to the relationship and to the deemed caregiver) of decisions that put one partner's career on hold to be primary caregiver to children or elders? We need to challenge ourselves to invent interventions that will impact all (not just female) family members' ethics regarding caring. But to do this we need broader social change. Work force norms must change. Changes in policy while helpful (e.g., family leave policy) must become part of the culture for both *men* and women. And, measures must be enacted on both micro and macro practice levels that will provide accountability for men and others in power to make changes in the distribution of power and privilege.

Consciousness raising is important and social work/family therapy should focus there, but it is not enough. Both my brother and I are feminists, and yet our caregiving "choices" were socially programmed early on and reinforced in our social and work lives. We saw the disparity, but our lives were structured to reinforce it. Broad based social changes are therefore needed—in the language we use (e.g., from "choice rhetoric" to discrimination), the work force, and social policy (Williams, 2000, p. 14).

How do we love fully in the midst of inequity and profound loss? I return to Chodron's (1997) message to use each

moment in life, especially the difficult ones, to learn to wake up. And, waking up to our shortcomings, our humanness requires that we open our hearts first to ourselves and then to others—with a spirit of compassion and forgiveness.

Life is a good teacher and a good friend. Things are always in transition, if we could only realize it. Nothing ever sums itself up in the way that we like to dream about. The off-center, in-between state is an ideal situation, a situation in which we ...can open our hearts and minds beyond limit (Chodron, 1997, p. 10).

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