

Shit, Stress, and Sacrifice: The Lived Experiences of Women's Cross-Generational Caregiving

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SETTING THE SCENE

The following script was written to be performed as a "Reader's Theatre" presentation. Reader's Theatre is "a staged presentation of a piece of text or selected pieces of different texts that are thematically linked" (Donmoyer & Yennie-Donmoyer 1995, 406). It is an oral interpretation in which scripts are held and read rather than acted and vocal expression is used "to give the listener a vivid picture of the action" (Dixon et al. 1996, 13). You as the audience are invited to create meaning from what is conveyed in the text.

The objective of this Reader's Theatre is to use our personal narratives to bring to life and critique the academic literature relevant to women's caregiving. The intention is not to provide answers, but to stimulate a lively discussion about caregiving in a society that has thus far refused to recognize and value essential emotional labour; labour that is provided mostly by women. Reader's Theatre, a non-traditional format (Brodie & Wiebe 1999; Ellis & Bochner 1996), was chosen to invite inspiring and meaningful dialogue. We hope by the end of the presentation the audience agrees that many women's lives are worthy of recognition for what we accomplish in a day, what we fail to accomplish, and the price we pay for the attempt.

We are white, middle-class, middle-aged, doctoral students living in a large Saskatchewan city. One of us is native to the province; two are from rural backgrounds and are the first in their extended families to attend university; the third is from a large metropolis in eastern Canada with university-educated parents. As highly educated women, we are equipped to search for solutions to the problems that naturally arise from our caregiving responsibilities. We are able to gain access to information, ask relevant questions and therefore make informed decisions. On the other hand, our financial resources are strained by educational costs and lack of full-time employment. We realize that our unearned privilege might, for us, open doors that are closed to others.

One of us considers herself part of a single

female-headed family with her aging parents living next door. Another is part of a blended heterosexual family that includes her daughter and her male partner. Her aging mother now lives in a nursing home in the same city. The third one of us identifies as a single lesbian whose mother lives in a small town in another province.

In this paper, we are not dealing with issues that arise for women of other positionalities. We do not have the lived experience of these other women, and we are not inclined to appropriate the experiences of others. However, to set our experience in a wider context, we draw on literature of North America and British origin.

THE SCENE

We ask that you, the audience, imagine the following scene: three academic women sitting around a table cluttered with books, papers, pens, pencils, and coffee cups, discussing their caregiving experiences, the related literature they have been reading, and bits and pieces of narratives they have written. The conversation has already been underway for some time.

THE SCRIPT

Liz

Bowel incontinence, now that's a good thing, at least from the point of view of the caregiver who is at the end of her rope and desperately needs her aging parent to be admitted to a nursing home. Compared to most other disabilities, bowel incontinence is an almost-certain ticket to qualifying for admission. On the other hand, there seems something so unnatural about changing your mother's diaper. At least when I do the job, I can be sure that her skin won't get punctured. Most aides don't have the time to read the medical chart, so how could they know that her skin has been thinned by years of taking steroids? Even those who do read the alert don't want to cut their nails, and garlic cloves only work on Dracula, not nurses with long nails... I roll her to one side of the bed, scoot out the soiled diaper, and slip the fresh under the freed hip. Then, I help her shift over to

the other side so I can repeat the steps. When she cries out in pain from even this small amount of movement, I relieve my own anguish by muttering: "damn those diaper manufacturers anyway. Don't they know that not everybody carries fifty extra pounds around their hips? And the tags, why are they never in the right place? And once they're opened, they always stick to whatever they're not supposed to." It strikes me how reciprocal this all is: she changed my diaper, now I'm changing hers. She pushed me in the stroller, so now I push her in the wheelchair. But there are differences. She knew it wouldn't be long, with a few months of concerted potty training, there'd be no more need for diapering. She had my increasing independence to look forward to - I can only expect the opposite... I feel her despair, her shame of having to depend on anyone to change her diaper, and I'm furious that I'm the one "chosen" to perform the unpleasant task. Just when I think "that's it, that's the last diaper I'm changing," Mom cracks another one of her witty jokes. We have a good laugh together and agree that we wouldn't miss any of it for the world.

Lenora

Yes Liz you must be run ragged with this, especially since you still have a child to look after. You know, women in middle age have been described as "the sandwich generation": sandwiched between the demands of childcare and eldercare. As the filling of the sandwich, women are being squeezed with no period of respite between child-rearing and caring for elderly parents and relatives. In fact, the childcare is often not completed before the necessities of eldercare begin, and even after children are grown and on their own, there are still caregiving roles required of women. The average North American woman spends eighteen years looking after her aging parents and seventeen years looking after her children (Alford-Cooper 1993). For over a decade, governments at all levels have been reducing funding for health care and eldercare. This has resulted in a devolution of responsibilities from higher levels of government onto lower levels and then onto families and individuals.

Liz

Well it's nice to know that somebody understands.

Lenora

Beverley, I've been trying to get a hold of you all week. Where have you been?

Beverley

I had to drive over to Manitoba to look after my mother for a few days. She had an operation on her knee in the outpatients' department in a small city about an hour's drive from the small town where she lives. You know, they don't want to keep you in the hospital anymore so

someone had to look after her. My brothers were not available. She needed someone to fetch and carry, cook and clean, and make sure she took the right medication. After a five-hour drive, I arrived to find her ready to call her doctor for help because she was unable to cope with the pain and prepare a meal for herself. Her welcoming smile when I entered the house told me more than words how relieved she was to see me.

Lenora

Although it must have felt good looking after your mom - being there and seeing her reduces some of your worry - I'll bet you came home really tired?

Beverley

Yes, but I don't think my experience compares with Liz's experience with her mother. Liz, do you have that little story you wrote about when your Mom was in the hospital down east? You should read it for Lenora.

Liz

Yes I have it, so here it is: It's late in the evening when I get another call from the emergency department of a Toronto hospital. They tell me my mother has suffered another stroke. Because the nursing home hasn't sent along a list of her medications, the emergency nurse asks me to identify all her meds, complete with dosages and schedule. After hanging up the phone, I prepare to catch the next flight. Never entirely emptied from the last trip, my suitcase already contains some of the necessary items: photo albums and a Walkman to help restore her post-stroke memory; a complete folder of all her medical records; and a picture of Mom when she was 23 years old to place over her bed so the staff see her as a person with intelligence, sensitivity, and vitality. Arriving at the hospital frazzled from worry, all the last-minute arrangements, the flight, and lack of sleep, it is the "parking-pass dilemma" that is, again, the last straw. I'm always on the lookout for a bargain and hospital parking lots offer great volume discounts: the longer your pass covers, the cheaper the daily rate. But the problem is I don't know how long I'm going to be needed, how long Mom is going to be in hospital. The first few days of a stroke, there is no telling how long or to what extent the recovery is going to be... When I pull up to the parking booth, all the stress, the worry, the exhaustion come tumbling out to the attendant. There is a huge line of cars behind me and, in typical big-city fashion, they are all blowing their horns to move me along, while I fall apart, and through my tears try to tell the attendant why I can't make the decision on what kind of pass to purchase. When I finally arrive in the emergency department, I am asked several questions about my mother's functionality. I tell the neurologist that my mother reads voraciously, attends regular rehab classes, and goes shopping and to concerts if she has a

companion. Pointing to the scan results, the neurologist responds, without hesitation, in a dismissive and condescending tone: "oh, you must be misreporting, according to these tests... [blah, blah, blah]," and she concludes with something to the effect that "this woman couldn't find her way to the bathroom." She might as well have said: "what do you know, you're only the daughter."

Lenora

Yes, you're only the daughter. As daughters, we're just assumed to be there to fill in the gaps, but don't dare presume to know anything.

Liz

That's right. It used to be, seven or eight years ago, when I would show up on the hospital ward, the nursing staff was very cautious about letting me go into the supply room. Now, they're all too busy to even notice. But, if they do, they're only too happy to see somebody pitching in and relieving them of some of the load. As I work together with a staff person to turn Mom in the bed or get her onto a commode or do any other two-person job, they often jokingly tell me they're going to authorize my licensing papers as a nurse. In turn, I ask them: "how does the payroll system work around here - is it direct deposit?" Yet, in the discharge documents written up by the attending physician, I'm identified as "a very involved daughter," which is code for "troublesome, demanding, and time-consuming."

Beverley

Yes, women are the problem and I have just been reading two authors who argue exactly that. Peter Peterson (1999) claims that the future of the developed world is threatened by the rising tide of older people and the heavy financial burden that they represent to government services such as pensions and medical services. Daniel Callahan (1987) emphasizes that women are the greatest part of this rising tide that is threatening the developed world because women live six to seven years longer than men and therefore will continue to become an ever larger proportion of the elderly population. Women pay for their extra years by experiencing more chronic illness and disability in those years, thus they require more medical services than do men (Fast & Keating 2000).

Liz

But women are also the solution. We are involved in caregiving activities from an early age; activities that restrict our access to the job market and result in being confined to low-paying, part-time jobs with little or no benefits. It is impossible for many women to accumulate the financial resources to support themselves in their later years. Caregiving activities such as pregnancy,

childbirth, child-rearing, home and relationship maintenance, partner care, and the care of elderly relatives are essential to the maintenance of our culture, but these activities are time consuming, unpaid, and undervalued by society (Fast & Keating 2000). Caregivers sacrifice time for themselves, social activities and relationships, and often neglect their own health. Eventually, they experience burnout, which, aside from everything else, reduces their effectiveness as caregivers (Dautzenberg et al. 2000).

Beverley

And even after the children have left home, you still have to look after them. They call you whenever they experience a new crisis. They still come to Mama for support and advice, don't they Lenora? Have you written that story yet?

Lenora

Yes, I wrote it the other day. Do you want to hear it?

Liz and Beverley

Yes, let's hear it.

Lenora

With its strident shrill, the alarm clock reminds me that it is time to get up. I groan as I reach to shut it off and peer one eyed at its luminous dial to make sure that it really is 5:30am. A long-distance phone call kept me awake last night. My daughter from northern Manitoba called. She is in the early stages of her first pregnancy.

"Mom?" she questions in response to my "Hello."

"Hi, Honey, how are you? It's so nice to hear your voice."

The muffled sounds of crying are all that I can hear on the line.

"Baby, what's wrong?" I question in a panic.

"Mom..." Her heartbroken voice comes through the phone. Between sobs she says: "There's something wrong with the baby."

Stunned, I question, "How do you know?"

"The standard tests that they did at my routine pregnancy examination showed an abnormality. I'll be flying out to Winnipeg for an ultrasound as soon as they can book an appointment. We need to know as soon as possible so that we can make an informed decision whether to terminate or not."

I don't know how to respond. Oh, my God! I don't

believe in abortion, but I cannot force my beliefs on her. Now is not the time. I have reared her to make her own choices.

"Oh, Baby, I am so sorry. I wish I could take away your pain."

We talk for what seems forever before she calms down. We both want this baby so very much. Finally we end our lengthy conversation with "I love you" and "I love you, too."

I immediately recall last night's conversation as I begin to do the muscle stretches that will allow me to get out of bed without too much pain. The Fibromyalgia is at its worst in the early morning. Then, my mind kicks into high gear. Is my stepfather up yet and has he taken the medication out of the refrigerator? The medication has to be at room temperature for half an hour before I can administer it. I am administering IV meds for an infection that my stepfather is experiencing. The Home Care nurses have trained me to flush the IV with a saline solution, administer the antibiotic over a five-minute period, and again flush the IV with saline. A few years ago Dad would have been hospitalized for about a week. Now the responsibility has been placed on the family, and since I am the eldest and nearest daughter... I must run over to my parents' house three times a day: 6:00am, 2:00pm, and 10:00pm. I will do this for the ten-day round of antibiotic treatment. In addition, I will take Dad to the doctor for a check-up every few days. Fortunately, Dad has taken the meds out of the fridge and they're ready when I arrive. A quick look at the IV site, however, reveals blood in the transparent tube. This is something new and I don't know what to do. I'll need to phone the Home Care nurses in order to get some guidance... How on earth am I going to manage today? I haven't even had my shower yet and I'm supposed to present a paper in my research class at 8:30 this morning. Now my whole day will be in disarray. Maybe I can grab a quick shower at my parents' house while waiting for the nurse to call me back.

That's what I've written so far.

Liz

That's something! You're right Lenora, there's just so much; when does it ever end, if it ever ends? Like two years ago, the extraordinary demands of long-distance caregiving became overwhelming, and I moved my Mom so that she and I could live in the same city. After numerous phone calls, letters, and meetings with medical staff, my district board representative and my MLA, finally Mom was assessed as being eligible for publicly-provided long-term care. I thought, finally, I

could hang up my nursing cap. Wrong! Now that she is in a nursing home, I find that there is never enough staff in the facility. Inevitably, when I go to see her, I end up doing the toileting, helping to change her clothes, cutting up her food at mealtime, or getting her from the wheelchair into bed. Then, there are always things that are needed to improve her quality of life, things that staff are not paid to do: obtaining and bringing her favorite foods to her; writing to her few remaining friends; purchasing clothes (many of which need altering to better suit the aging, disabled body); taking her to regular medical and dental appointments; refilling her stock of incontinence supplies. When I'm not actually providing the care, there is an infinite amount of coordinating, negotiating, and compromising, all of which requires a fast-track medical degree and the savvy and skill usually only credited to high-powered financial dealers and mediators of union-management disputes.

Lenora

Well, your experience, Liz, matches with what the literature says. Finnegan Alford-Cooper (1993) lists the many tasks undertaken by caregivers that go well beyond the hands-on care. These include administrative functions to deal with financial and legal matters, which are often very time consuming. Is it any wonder that caregiving becomes a full-time job?

Beverley

You know, Emily Abel (1997) estimates that the cost of replacing women's unpaid eldercare in the US would be \$9.6 billion per year. Robyn Stone (1997) claims that in comparison to elderly women, more elderly men have a female relative or spouse to care for them. So, not only are many elderly women going without care, they are themselves providing care. In addition, most employed women continue with their employment even after assuming the responsibility for the care of an aging parent (Atienza & Stephens 2000), and there is no significant difference in the number of eldercare hours provided by employed caregivers and unemployed caregivers (Dautzenberg 2000). Yet, writers like Peterson (1999) and Callahan (1987) suggest that the answers to the eldercare problem lie in placing more emphasis on familial obligations and in women bearing more children to share the increasing economic burden. As Finnegan Alford-Cooper (1993, 50-51) writes "[society has] an expectation that families, particularly women, will not only continue to provide the bulk of eldercare, but will somehow increase the amount of care they are giving."

Liz

And, the gender divide is quite clear: Emily Abel (1997) quotes a British study that found that women spend nineteen times more time caring for elderly relatives

than do men.

Lenora

Well, when you mention the amount of stress that eldercare imposes on women, it makes me think of the problem of "granny dumping" (Alford-Cooper 1993): caregivers abandoning their aging relatives at emergency departments because they can't cope with the stress anymore and they have nowhere else to turn. Some states south of the border have introduced legislation to allow the state to charge and impose heavy penalties on the "granny dumpers": those burned-out caregivers.

Liz

Most caregivers are well aware of how limited the care is in any hospital, so I can only imagine how stressed a caregiver has to be to "dump" her aging parent on the doorstep of an emergency department. That reminds me of my experience at a family conference I was called to not long ago to discuss my mother's continuing care needs. The meeting was at the Geriatric Assessment Unit of the hospital where Mom had been for the previous three weeks. In addition to myself, my partner and my daughter, those in attendance included the operator of the personal care home where Mom was living prior to her hospital admission, and members of the unit's staff: social worker, physician, speech pathologist, head nurse, physiotherapist, and occupational therapist. By the way, recent episodes of Mom's hospitalization have left me with a profound appreciation for the increasing pressures experienced by health care workers at all levels of the institutional structures. My expectations have gradually adjusted to better harmonize with the new realities. Despite this, I was completely unprepared for what transpired at the family conference. Several times during the meeting, my mother was assigned characteristics of an inanimate object in such patronizing statements as: "oh, she is such a frail little thing." More than once Mom was referred to as "a total dress" and "a total feed." Worse still, by all appearances, the reporting staff were entirely unaware of the appalling lack of sensitivity, of how degrading and depreciating their words were. She had become totally dehumanised: an object. My mother is enjoyed, admired, and loved by her family. With her insightfulness, humour, and optimism, she continues to contribute to those around her. Her lifetime accomplishments have been both noteworthy and many. My mother has proved herself to be a human being deserving of compassion and respect. But, how can she possibly expect this from those who consider her to be "a total dress" and "a total feed"?

Beverley

So you had a choice to make: either you let them do it

their way (caring for your mother while they view her as "a total feed") and you step aside or you take her home and commit yourself to caring for her full-time, and they will step aside. They sure don't leave you any middle ground, do they?

Liz

No, there isn't any compromise that is acceptable to them, and that's what makes the decision so difficult for me. If I choose the first option and leave her to them, then I will feel like I have abandoned my own mother to be left in the hands of people who would not possibly care for her the way I think she deserves!

Lenora

And, if you choose the second option and care for her yourself, then they can say that you are just another one of the many female caregivers who don't make use of the "available" services. Some researchers speculate that many women refuse services because they confuse "providing care" with "caring." If women themselves are not providing all the care their aging parents need, they think it indicates a lack of caring about their parents (Alford-Cooper 1993). But, here again, the problem is identified as the individual caregiver's deficiency, instead of taking a wider view to incorporate the social, systemic problems.

Beverley

It is not only eldercare that burdens women; some are still responsible for children at the same time as they are responsible for their aging parents. How is your daughter, Liz? Tell Lenora about your recent experience when Andrea was in the hospital.

Liz

Not long ago, my daughter had a ruptured appendix and was rushed into hospital for emergency surgery. She was released a week later, but after a few days of being at home, she was readmitted with a recurrent infection. As she began to rally during her second hospital stay, I began to worry about the impending discharge. The physician and staff agreed that Andrea had been released from hospital too soon the first time, but I was assured that this time it would be all right because we would have the benefit of the Home IV Program. This would allow Andrea to continue with the intravenous antibiotics to reduce the chances of yet another infection, while enjoying the comforts of her own home as she recuperated fully. Eventually, the time came for my daughter to be released. The physician had completed his discharge notes, her bed sheets and towels were on their way to laundry, wilted flower arrangements were tossed in the garbage, and her belongings were all packed and ready to go. The only remaining detail was to speak to the social worker who

was to make the arrangements for the Home IV Program. As Andrea and I enter the social worker's office, the paperwork is put before me with a request to sign on the dotted line. Unsure about what I am about to sign, I ask a few questions about the Program: "How often would a nurse be around to check? What happens if the medication bag empties before she arrives?" And so on. After only these few questions, it is acutely obvious that there is no Home IV Program, no nurse making home visits, just a few minutes of instruction while the RN hooks up the equipment, and then a telephone number to call when you run into difficulty. Having spent the previous few weeks watching nurses responding to the beep-beep-beep of the IV (replacing bags, adjusting the rate of flow, and calming the machine and the patient when either would complain), I knew I was not qualified to take on the job. Even Licensed Practical Nurses, who complete more than a year of training, are not licensed to run IVs. How could I possibly do it? And yet, there sitting beside me is my child traumatized more by hospital life than by her physical illness; a kid I've had to bribe with at least one mock cocktail for each day that she was on her best patient behaviour. How could I say no? How could I be so cold-hearted as to deny my own daughter the comfort of sleeping in her own bed while she was feeling so rotten? My decision to refuse the "Home IV Program" was met with fury in equal amounts from what had up until then been opposing camps: the staff and the patient. I had no choice but to raise the "ante": along with the mock cocktails, I promised platters of deep-fried chicken wings, and I delivered yet another round of chocolates to the nursing staff.

Beverley

Well you can easily calculate the cost of the chocolates, the financial costs can be approximated, but many of the personal costs to women who must shoulder the major portion of the burden of eldercare and childcare are not quantifiable. Women suffer from the physical strains of hard labour (for which they are not trained), and this may result in an early deterioration of their own health. The emotional strains between the primary caregivers (women), those being taken care of, and other family members can result in the breakdown of family units. This too will echo down through future generations impacting on the eldercare of those who have not yet reached that point in their lives.

Lenora

So what are the solutions? And I don't mean telling me to do more than I am already doing.

Liz

Much of the policy discussions concentrate on the workplace, since many women are combining their

employment and caregiving roles. Writers such as Audie Atienza and Stephens (2000) suggest that employment policy needs to encourage employers to provide flexible work schedules, family illness leave options, counseling services, and even adult day care. The difficulty with these proposals is enforcement. Many employers are not convinced that these initiatives have sufficient returns, in terms of increased productivity, to warrant the costs.

Lenora

Peterson (1999) suggests that people should work for more years, that more emphasis should be placed on familial obligations, and that the young should be encouraged to have more children to bear the burden of eldercare. By age 65, most people have spent over two thirds of their lives managing the stress of work-relationship conflict, stress that results in physical and emotional health problems. We cannot depend on support from family members, especially voluntary support. Familial obligations would have to be legislated and enforced. But, solutions such as anti-"granny dumping" legislation only exacerbate the problems that women already suffer as a consequence of their caregiving roles.

Beverley

Callahan claims that the only real solution is to implement age-based rationing of medical health services. He defines rationing as "the denial or limitation of forms of health care that would be both desired by individuals and beneficial to them" (1987, 190). It is true that compared to previous generations, today's elders, especially women, live longer and tend to have multiple, chronic disorders instead of dying rapidly from infections or accidents (Statistics Canada 2001). But Callahan contends that our economic system cannot manage the increased burden of older women, in particular, because "they are more likely to be poor, to live alone, and to require institutionalization for their diseases and disabilities" (193). So, Callahan freely admits that age-based rationing would fall much more heavily on women than on men, and this imbalance could be seen as discriminatory. However, he argues that his solution is justifiable because "women would fail to get what dead males already fail to get as well; it is thus not as if women are being denied a benefit that men get" (194). This is a pretty plain statement that older women have no more value than dead men.

Lenora

With this type of thinking, women may have much more to fear than they think.

Beverley

So, what you're really saying is: "You think you've got it bad now as a caregiver; just wait until you're on the

receiving end of the caregiving. Then see what little value you have" (Fiore 1999).

Lenora

Women tend to individualize the problems arising from their caregiving responsibilities. They attempt to find their own solutions rather than imposing on others (Alford-Cooper 1993). Women are so tied up in the caregiving activities that they often fail to truly reflect on the roots of their problems. Baba Copper (1997, 1986) has pointed out that aging is a natural process. All persons must learn to adapt to and cope with it. Aging is not merely a personal problem; it is a political and societal problem because of the way we have structured life in this society.

Beverley

One partial solution would be the implementation of a guaranteed minimum income. If we really value human life, then every person born on this earth should be entitled to a share of the earth's resources sufficient to sustain life at a decent level. A guaranteed income from birth to death would be a step in the right direction; however, even this "radical" solution fails to address the problem of the devaluation of women and women's activities that make the continuation of our cultures possible. I believe that in the long term, a real solution must be built by restructuring society, a society that places more value on care and compassion than on violence and competition.

Liz

You're right! We are tired of being perceived as "the problem" and also expected to be the solution.

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