

# Perspectives on Caregiving

by Jacqueline Low

*En se basant sur son «propre vécu», l'auteure raconte son expérience de femme qui s'occupe d'une personne atteinte de maladie chronique. Elle analyse les convergences et les contradictions qui existent entre ses propres expériences et connaissances et celles qui sont documentées dans les ouvrages qui traitent de maladies chroniques.*

I was seven years old when my mother first became ill. For several years, she had endured severe headaches. I have vivid memories of finding her lying in a dark room wearing wrap-around sunglasses, trying to shut out all sensation. Emergency brain surgery revealed that the source of the pain lay in multiple aneurysms of the brain, one of which had ruptured. Three of the aneurysms were successfully treated while the final aneurysm, located in an inoperable part of the brain, remains untreated.

One consequence of the surgery was injury to her right eye resulting in severe double vision. Subsequent surgery only partially corrected the damage and failed to prevent further deterioration. Also resulting from the surgery was petit-mal epilepsy which manifests in sporadic losses of balance and consciousness. A further devastating consequence concerned the combined affects of congenital arterial sclerosis and one of the several post-operative angiograms performed. This particular angiogram caused the collapse of an artery in her groin, resulting several years later in the amputation of her right leg above the knee. Following the amputation, she has used a prosthesis and canes, but her general condition has since weakened. She now uses a walker and wheelchair to get around. In the years following these initial health crises, she has had two heart attacks, two strokes, and breast cancer, requiring a radical mastectomy, twice over. She has lived in considerable pain and relative isolation for the last eighteen years.

## A daughter's experience of caring

Except for comparatively short periods of hospitalization my mother has been cared for at home. My father, brother, and I have cared for and cared about her in a variety of ways: from bringing her meals and helping her bathe, to carrying her up and down stairs and dressing her wounds. I have always understood caring for my mother as exceedingly normal, however much I have resented it at times. As Reistma-Street points out, this is not unusual as girls learn to care early in life. Despite differences in behaviour and lifestyle, an often unspoken legacy of caring is passed down from woman to woman. As I look back over my personal history, these lessons are clear. Before she became ill

my mother was a full-time homemaker who took care of my brother, my father, and me. My grandmother, widowed when my father was six months old, cared for her son until he married and for her aging parents until they died. When my mother was first hospitalized, Grandma came and cared for us. She died last summer in a nursing home. When I was eight or nine years old, I was taken to visit Great-Aunt Lillian as she lay dying in a nursing home. She had spent her life taking care of her chronically ill parents.

During my life I have witnessed a succession of women, professionals and non-professionals, family members, and non-family members, who have given care while being less often the recipients of care. I have also been exposed to examples of men who care. My father and brother were as likely as I was to cook, clean, and otherwise nurse my mother. There was a minimal division of labour in our household based more on age and availability than on gender. My mother may have preferred that I help with some of the more intimate tasks, but my brother and father also did them. After my brother and I left home, my father became responsible for the majority of caregiving. I now live in another city and do almost none of the day-to-day care.

## Insights on caring

I find it somewhat ironic writing about my mother in the context of women and disability simply because 'disabled' was never a concept used in our family. My mother would talk about her leg, her head, but even after the amputation she never identified herself and we never thought of her as 'disabled.' While others may interpret this as a grand act of denial, I see it as a genuinely normal response. It is normal in the sense that it was and is our family's way of coping with a series of catastrophic illnesses.

While my mother's hair was growing back after brain surgery, she wore head scarves which coordinated with her clothes. When her leg was amputated, she adjusted her wardrobe to camouflage her prosthesis. She often restricts her activities for several days in order to attend a reception or go out to dinner. I bought her a fancy shoe bag so she can carry her medical supplies unnoticed. We had bars installed in the bathroom so she can manage with a minimum of help and we carry her up and down stairs when we travel. These are only a few examples of the many adjustments we made in accommodating and normalizing chronic illness; adjustments which immediately became part of our normal every-day-life. However, that we experience our life as normal does not mean that it is not problematic. My mother's efforts to

live 'normally' often conflict with our efforts to take care of her. When she tries to do things that she is no longer physically capable of doing, it not only frustrates her, it can be dangerous. She may try to use the bathroom without help only to lose her balance and fall crashing onto the tile floor. For her, coping is an act of balancing between rejection of a role which is limiting and accepting physical limitations.

Caring about her can also come into conflict with caring for her (Baines, Evans and Neysmith). When expediency dictates that we treat her like a child—making her rest, telling her it is easier

also obscures the processes by which men learn or do not learn to care. As Baines, Evans, and Neysmith note, caring taken on by men like my father and brother is "viewed as exceptional" (22) as it does not conform to traditional patterns of caring. I see my brother and father not so much as exceptions, but as examples of the potential elasticity of gender roles. For lack of a more appropriate concept, I have seen the 'feminization' of my father and brother, their rapid socialization into caregivers. Future research would do well to examine how men learn to care.

Further, at times, the literature on chronic illness fails to

***An almost saintly quality is attributed to individuals with chronic illness and those who care for them. The person who is ill is brave and stoic, the caregivers are selfless and tireless.***

for us to do things ourselves than to help her do them—caring about her makes pragmatic action difficult. Perhaps the definitive example of this sort of contradiction concerns the idea of institutionalization. My mother should have twenty-four hour care which we are unable to afford financially or otherwise. It has been suggested that a nursing home is the rational solution to caring for my mother, yet caring about her means that we do not consider this an option.

#### **Personal experience as epistemological work**

The importance of the personal within scholarly work is a long-standing tradition in feminist analyses. It has been less of an accepted tradition in mainstream sociological research (Paget). However, Paget argues that within the phenomenological perspective of sociology, the subjectivity of the observer and the subjectivity of the observed are both a necessary part of the research process. The influence of the sociologist's experience is unavoidable.

My own experience caring for my mother has necessarily informed my studies in medical sociology. I find my experiences are often mirrored in the literature on caregiving and chronic illness. For instance, Finch argues that there has never been a "golden age" where the elderly and infirm were cared for exclusively within the family. Nor are we approaching a time where care will be the responsibility of institutions outside the family. Rather, over time, families have had differential access to resources of caring within particular historical periods. These periods are marked by specific systems of social support for and different economic constraints on those responsible for individuals in need of care. *Who* cares is a product of the conjunction of particular family resources and particular socio-cultural conditions.

On the other hand, the same experience allows me to criticize the literature on caregiving, which often fails to adequately account for men's caring. While I don't mean to argue that women are not responsible for the majority of care given, it must be stressed that this is not inherent in our biology (Aronson). The myth of nurturing or caring as exclusive to women not only obscures the processes by which women become caregivers, it

appreciate the paradoxes inherent in the experiences of caregivers and those of individuals dependent on care. If the sick role is too deeply internalized, it can dehumanize. If it is too successfully rejected it can be dangerous and/or conflict with the efforts of others to give care. Similarly, as Aronson and Briggs point out, feelings of love and commitment often conflict with feelings of guilt and resentment.

An almost saintly quality is attributed to individuals with chronic illnesses and those who care for them. The person who is ill is brave and stoic, the caregivers are selfless and tireless. The ill transcend their personal catastrophes to live full and happy lives. Fighting against disability brings the caregivers and receivers of care closer together (Corbin and Strauss). While similar scenarios are possible, it is naive to suggest that they are the norm. Outsiders to our family often tell us how wonderful we are. While we are not terrible people, the truth is that we are not always wonderful. My mother can be demanding and irritating and my brother, father, and I can be short tempered and insensitive. The point is that we sometimes do not transcend the disasters that befall us and sometimes misfortune does not bring us closer together. More precisely, coping with chronic illness is better conceptualized as a continuum between stoicism and trepidation, selfless caregiving and self-centred resentment, coming together and alienation.

The conventional focus on deviance in the literature obscures the degree to which normality is experienced by families coping with crises in health (Bogdan and Taylor). Future research must take these contradictions into account and recognize differences in access to resources and ways of coping with chronic illness and/or disability.

*Jacqueline Low has a Master of Arts from Concordia University and is currently pursuing a doctoral degree in sociology at McMaster University. Her area of specialization is medical sociology and her specific interests include alternative health practices and the socio-cultural meanings of health.*

*She would like to thank Dorothy Pawluch, Jane Aronson, Yvonne Werkmann, and Karen Barber for the help and encouragement they gave in writing this paper.*

## References

- Aronson, Jane. "Dutiful Daughters and Undemanding Mothers: Contrasting Images of Giving and Receiving Care in Middle and Later Life." *Women's Caring: Feminist Perspectives on Social Welfare*. Baines, Evans, and Neysmith, eds. Toronto: McClelland & Stewart Inc, 1991.
- Baines, Carol T., Patricia M. Evans, and Sheila Neysmith, eds. *Women's Caring: Feminist Perspectives on Social Welfare*. Toronto: McClelland & Stewart Inc., 1991.
- Bogdan, Robert and Stephen J. Taylor. "The Social Construction of Humanness: Relationships With Severely Disabled People." *Interpreting Disability: A Qualitative Reader*. Philip M. Ferguson, Dianne L. Ferguson and Stephen J. Taylor, eds. New York: Teachers College Press, 1992.
- Briggs, Anna and Judith Oliver, eds. *Caring: Experiences of Looking After Disabled Relatives*. London: Routledge & Kegan Paul Publishing Company, 1985.
- Corbin, Juliet M. and Anselm L. Strauss. *Unending Work and Care: Managing Chronic Illness at Home*. San Francisco: Jossey-Bass Publishers Inc, 1988.
- Finch, Janet. *Family Obligations and Social Change*. Cambridge: Polity Press, 1989.
- Paget, Marianne. A. "Life Mirrors Work Mirrors Text Mirrors Life." *Social Problems* 37(2) (1990): 137-148.
- Reistma-Street, Marge. "Girls Learn to Care; Girls Policed to Care." *Women's Caring: Feminist Perspectives on Social Welfare*. Baines, Evans, and Neysmith, eds. Toronto: McClelland & Stewart Inc, 1991.



Winsom, *Untitled*. Acrylic on canvas, 22cm x 28cm.

## DIANA THOMPSON

### Hospital

The doctor  
doesn't feel your pain  
he can insert  
his plastic fingers  
between your boneshafts  
slide his alcoholic knife  
through muscle  
as easily  
as any madman  
holds his weapon  
beneath your skin

Think of this: your body as  
a wet rag laid out  
on a table like a pig for a feast;  
decipherable, wine-red  
corpse without  
guilt to be maimed  
scribed like a target,  
war-zoned, mapped.

The only pity  
is your consciousness  
like glass shards in your guts  
a bit of clutter  
to be put aside

*Diana Thompson is a poet and artist who lives on Salt Spring Island in British Columbia.*



Carrie R. Cardwell, *The Critical Woman and the Space Cadet*, 1993. Acrylic on canvas.

This painting is about my perception of language as a hard-of-hearing / deaf woman. Moving and transitioning between deaf and hearing worlds is painful. Growing up, I repressed spontaneous verbal communication. Also, external barriers existed, such as lack of exposure to the deaf community and American Sign Language (ASL).

I developed non-verbal communication primarily through art and dance to compensate. I want mutual understanding and connection, like most people, and can also hate this need. To truly belong requires that I dismantle prickly defenses, represented in the painting by the woman on the left.

Otherwise, I may "space out," not really understanding what is being said (signed or voiced). The woman on the right stares vacantly into space. Then, the critical hand on the far right points at her, calls her dumb. The hand, belonging to the woman on the right with the dunce cap, says "Stop."

The work of dealing with loneliness, a human condition, remains. But forming more satisfying relationships is easier by understanding myself in a deaf context. Relating to deaf people and those in the community, such as interpreters who are also bi-cultural, has been instrumental in maintaining my Self.

*Carrie Cardwell is a deaf woman who has worked as an art therapist with deaf and hard-of-hearing people for nine years. She currently works in an outpatient clinic for deaf adults in Toronto. She has a deaf husband and a sixteen month old son.*