Feminizing the Multiple

by Karen A. Blackford

Cet article retrace les changements philosophiques et politiques ainsi que les actions prises par la Société canadienne de la sclérose en plaques au cours des années. Des changements subtils de la part du Mouvement des femmes et du Mouvement pour les droits des personnes qui présentent des handicaps ont indirectement transformé la façon dont les femmes handicapées, leur féminité et la forme de leurs handicaps sont perçues par la Société.

As a woman with a chronic illness who is also a mother, I know that there are strong societal barriers to mothering with a disability. Women with disabilities have generally been either prevented from having children or constrained when they become mothers (Asch and Fine; Mathews). Constraints often come in the form of inappropriate or inadequate support services (Ridington; Dunn; Blackford, 1993b). Canadian researchers, including feminists, have rarely recognized that disabled mothers exist, much less identified where or how mothers with disabilities have been oppressed.

Over time, however, the Multiple Sclerosis (MS) Society of Canada has begun to recognize and to address the concerns of mothers with disabilities on their own terms. I call this transition a process of feminization.

The MS Society of Canada is an appropriate focus for an exploration of notions of disability and motherhood. Many more women than men have multiple sclerosis (Wakesman, Reignold and Reynolds) and symptoms usually emerge during childbearing years. Thus the MS Society claims to speak for many women with disabilities. Newsletter publications from the beginning of the MS Society provide a window for viewing how notions about mothers with disabilities have emerged historically, and the interactive way in which change can occur over time.

Medicalization

Medicalization implies that medical diagnosis, treatment, and monitoring are essential for persons with disabilities. It suggests that in planning her life style, a woman with a disability should make the demands of the medical regime her priority. This discourse reflects the belief that disability is a problem located in the individual who must be ‘fixed’ and overlooks the extent to which disablement is socially created (Oliver).

Ideas of medicalization are based on the male-centered Western notions of rationality, individuality, and normalcy. This ‘normal’ body is male, with females existing to perpetuate the male lineage. The ‘normal’ body is white-skinned and Caucasian, with people of other races being viewed with suspicion. The ‘normal’ body is the perfectly healthy able-bodied one, which means that persons with disabilities are often not considered when transportation is planned or prenatal classes are organized. The values of normalcy and rationality also assume that through the superiority of scientific theory, ‘mankind’ can transcend the body and nature. Therefore ‘man’ can and should control nature.

From its earliest newsletter editions, the MS Society clearly states its main purpose: to raise money for biomedical research into the cause of multiple sclerosis—essentially in order to control nature. From 1957 onward, editorials suggested that “by supporting every medical research programme approved and authorized by our Medical Advisory Board” contributors would be making 1958 (or subsequent years) the “MS (Mystery solved) year of our Society” (The Bulletin, 4). Always we read about a “stepped-up demand for research support.” The “stepped-up” nature of these demands is clearly based on the wishes of Medical Advisory Board members (MS Canada, Autumn 1977: 3).

The notion of saving the afflicted

For humanitarians, medicalization was justified by the need to be charitable and to save those who were “afflicted” with what was seen as the personal tragedy of multiple sclerosis. Women with MS and their children were portrayed as tragic victims, “afflicted by this malady” (Multiple Sclerosis, Nov. 2, 1968: 10), “suffering,” and “needing gentle care” (5). The inverse of the tragic figure is the individual hero. In the case of the MS Society, we see women with MS portrayed raising funds as Ladies Auxiliary organizers "al-
though handicapped with a wheelchair" (The Bulletin, 2) or selling Halloween candy (Multiple Sclerosis, 1968, (1): 8) and cook books.

That women with MS might be mothers as well as fundraisers, was a secret rarely divulged to readers until 1975 when the following slogan appeared:

Support multiple sclerosis research. Buy a carnation for Mother's Day...

Taking the link the MS Society has with Mother's Day and Father's Day, the chapter came up with the idea of selling flowers before Mother's Day. (MS Canada, Winter 1975: 1)

Finally, people with MS could be mothers or fathers. Yet, having gone this far, the fabric of life associated with parenting with multiple sclerosis was not portrayed. Instead, the notion of parenting emerged only as a symbolic advertisement of hearth and home to raise research funds. Invisibility and commodification of these mothers occurred through a combination of forces including disability stigma, a notion of the private sphere in which childhood and procreation should be hidden from 'proper' public view (Ryan), and the discourse of medicalization.

Social control of mothers with multiple sclerosis

Newsletter photographs of women with multiple sclerosis in hospital gowns as research subjects (Multiple Sclerosis, 1968 (1): 15) situated them under laboratory conditions, objectified and separated from society. Frequent reports of research findings pointed to germs, viruses (The Bulletin, 1; MS Canada, Summer 1975: 2) or malformed genes (MS Canada, June 1985: 4) as possible causes of MS.

Rhetoric about viruses created fear of getting close to people with MS. Nineteenth century history shows that a miasma theory that disease was caused by garbage fumes (Wohl) kept the upper classes fearful of contact with poor, disabled, or immigrant persons in Britain during the Social Purity Movement. Claims about genetic causes for MS are reminiscent of eugenics ideology during the Boer War and World War II, when the nation's future was thought to be "rooted in the mothers physique" (Wohl, 16).

Power brokers: physicians and middle class women

The power which physicians have had in determining the direction of the MS Society of Canada is clear from its first organizing meeting in Montreal. By the end of the 1948 meeting, a Medical Advisory Board had won responsibility to decide how the bulk of money raised would be spent. In 1982, the Medical Advisory Board enlarged its mandate to include input into policy issues (Fraser, 10). Physicians maintained power by presenting themselves as servants searching for the key which would "help unlock the mystery of MS" (The Bulletin, 1). As credentialled medical authorities, they protected persons with MS from quackery (MS Canada, Summer 1975: 6-7). Their medical research provided Canadians with nationalist pride through international publications (MS Canada, 1976, 2).

Just as middle class women allied with physicians for earlier purity reforms in Britain (Mort), middle class Canadian women supported the medical model of multiple sclerosis. The 1957 edition of The Bulletin provides many excellent examples of alliances between the MS Society and middle class women in Lions Clubs and Junior Leagues.

The first Canadian chapter of the (American) Multiple Sclerosis Society was founded in 1946 by Evelyn Opel, a mother diagnosed with multiple sclerosis. After she heard from her physician, R.C. Russell, about his experiences attending MS Society meetings in New York (Fraser), she formed a Dr. R.C. Russell chapter of the American organization. In 1948, she went on to found the MS Society of Canada, with Dr. Russell as head of its first Medical Advisory Board. The Canadian Paraplegic Association had formed in 1945 as

"with the disease, I have been a wife, a mother, a nurse, a student, of these things. Just because I receive treatment or services does not give them the right to own me."
a self help group of disabled veterans (Tremblay). Yet Mrs. Opel apparently did not consider the self help model. Presumably, power differences related to gender and to the traditional doctor-patient relationship made Evelyn Opel a likely candidate for seeing organizational options and multiple sclerosis through Dr. Russell’s eyes. Her class position also brought her into affiliation with middle-class reformers and with the values of seeing MS as a “cause”.

Feminizing the organization

Chapter members, primarily women in towns across Canada, raised objections to the continual medicalization of multiple sclerosis, and demanded that more attention be paid to living with multiple sclerosis. However, they were unable to overcome control of policy and spending which rested in central Canada with the national office and the Board of Directors in the early years.

During the 1956-58 period the Society experienced some growing pains, as a result of the Medical Advisory Board’s requests for more research funds and the increasing number of chapters forming all across the country. So chapters felt that they should retain most of their funds in their own communities for patient services work. This was in sharp contrast to the policy of the board, which required that chapters keep 25 per cent of all funds raised for their own purposes, and pass on the remaining 75 per cent to the national research programme. The result was an increased emphasis on fund raising. (Fraser, 14)

During the 1960s and 70s, influence from the women’s movement, the disability rights movement (Wolf; Driedger), and the discourse of civil rights began to alter public opinion and Canadian society generally. The goal of finding a cure for MS drove all biomedical research directives until 1976. Finally, in that year, women with MS gained an unlikely ally in the Liberal federal government. The Ministry of Health insisted that federal research money, if allocated, must be used to seek improvements in the present life condition of persons with MS (MS Canada, 1976: 2). In spite of strong protests from physicians within the MS Society of Canada, the government held firm. As a result, occasional “research targeted at helping people with MS now” through projects to improve the physical quality of life with MS and MS was initiated (MS Canada, Autumn 1980: 4).

In 1974, a woman was appointed for the first time as national newsletter editor. Values expressed through publications of the Multiple Sclerosis Society of Canada have subsequently changed gradually, so that the existence and importance of family life with MS actually dominated its 1992 advertising campaign.

In 1977, a woman with MS finally inserted the voice and politic of the women’s movement (Wolf) and the disability rights movement (Driedger) into the pages of MS Canada. She chose to define herself:

I am not a Disease! During my twenty some years of experience with the disease I have been a wife, a mother, a nurse, a student, a research officer, a gardener, a swimmer, etc. I still am most of these things. Just because I receive treatment, or services from professionals or service organizations does not give them the right to own me. I do not belong to them. I do not relinquish to them the right to make decisions for me or to speak for me to my family, the public or the government. (MS Canada, Autumn 1977: 3)

Mothers with disabilities who discount themselves in order to fulfill what they ‘know’ to be the rights of their children to have an able-bodied mother deny themselves the right to be disabled. They simultaneously teach their children to deny disability.

Here is a woman and mother who openly resisted regulation by biomedical and organizational forces within the MS Society. She repudiates the label of either passive sufferer or research subject. Instead, she insists on creating distance between herself and a medical order which she dares to characterize as controlling.

A woman executive director was hired in 1979. The Individual and Family Services Division (IFSD) was formed in 1979, with a woman at its head. It established at least one coordinator in each province and introduced literature about family life. The newsletter promoted IFSD pamphlets titled Multiple Sclerosis: Its Effects on You and Those You Love and Should I Have a Baby? (MS Canada, December 1986: 5). In 1988, Plain Talk: A Booklet about Multiple Sclerosis for Family Members advocated making a priority of caring not just curing. This text emphasized ways to live more positively in the present, rather than focusing on research which might someday find a cure for multiple sclerosis.

In 1979, there was also a move to allocate resources equally between the financing of biomedical research and IFSD.

In 1988, the newsletter finally gives us a sense of what family life was really like for Evelyn Opel, her daughter and husband. For the first time we read, “She ... married in 1944 and had a baby girl ... the next year. Her devoted family life saw her through many personal struggles.” (MS Canada, April 1988: 3). Her daughter recalled “that her father had to carry her mother up and down the stairs to their apartment until they were able to find more accessible housing when [the daughter] was five” (3). Although the privacy veil of family life was now lifted, the discourse of medicalization continued. Mrs. Opel was identified as a “long-time fighter” and “MS Society Founder” (3). The passive victim of tragedy was reconstructed as a tragic hero.

Finally, the 1991 Annual Report shows that the organization’s mandate has broadened enormously. The following committees now report to the national board of directors: public relations, social action, individual and family services, fund raising, volunteer recruitment, medical policy, and medical advisory board.

Currently, discussion groups for chil-
Privileging particular ideas about what ‘normal’ means in terms of the two-parent, middle class Caucasian family, and the perfectly healthy body leaves no room for appreciating mothers whose bodies do not fit this ideal, or who are part of different family forms.

In this issue, both Sharon Dale Stone and Susan Wendell discuss transcending the body. Stone reminds us that when all our intentions are geared to overcoming or ignoring bodies, we discount and de-value part of who we are. Feminists before her have used this argument to protest against the marginalization of the female body. She writes to protest the marginalization of the disabled body.

Susan Wendell appears to take an opposing position. She questions feminist assumptions that transcendence of the body is necessarily wrong for women. Experience has shown her that the pain and fatigue of the disabled body is something which she deliberately transcends, by taking a rest or putting herself in a comfortable position, in order to then ignore her body for a time. She uses this time to move beyond the body with thoughts and creative ideas. She questions the one-sided perspective of feminists who absolutely oppose transcending the body through rationality.

Throughout this review of the MS Society, I have objected to male-driven scien-
tific ideas about transcending the female disabled body which lead to objectification and commodification. Since these ideas still dominate science, feminists must continue to question and to object strongly when advocating transcendence of nature hides a subtext of needing to measure up to some ideal male norm. Where science is used to control nature in this particular way we must argue for living in harmony with nature to some degree, and for appreciating the body in all its manifestations. We should insist on respectful recognition of difference, open dialogue, and the inclusive day-to-day social connectedness that is necessary for living with and nurturing each other in the present. Process is important, not just outcome.

However, while we should continue to advocate for living in harmony with nature in some form, and while we should definitely object to the masculine ideals currently dominate science, it is not helpful to create yet another competition between only two alternatives. Forced choices between objective/subjective, male/female, people of colour/Caucasians, humans/nature, have not gotten us very far. When we see living in harmony with nature as the only simple answer, we can create the world we want and need.” (Goodwillie, 104).

Theorizing about women with disabilities can broaden our understanding of feminist theory generally. Furthermore, a critical historical perspective of the values which keep us apart can bring us together.

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1The library of newsletters housed at the Toronto Offices of the MS Society of Canada includes only one edition of The Bulletin (No. 22, December, 1957), all editions of Multiple Sclerosis and all editions of MS Canada. Some of the newsletter analysis presented here has been described in a different article which focused upon moral regulation of disabled mothers in the MS Society’s early years (see Blackford, 1993a).

References


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