

WORKING PAPERS IN THE HUMANITIES 5

# Humanities Research Group



EXPANDING HEALTH CARE PERSPECTIVES:  
POLICY MAKING TOWARDS THE YEAR 2000

*Edited by  
Mary Louise Drake*

UNIVERSITY OF WINDSOR, 1996

LEDDY LIBRARY  
UNIVERSITY OF WINDSOR

Publications of the  
HUMANITIES RESEARCH GROUP

GENERAL EDITOR Jacqueline Murray

Working Papers in the Humanities 5

University of Windsor

Windsor, Ontario, Canada N9B 3P4



**EXPANDING HEALTH CARE PERSPECTIVES:  
POLICY MAKING TOWARDS THE YEAR 2000**

Proceedings of the Workshop held at the  
Humanities Research Group, University of Windsor,  
March 31, 1995

Edited by

Mary Louise Drake

**Working Papers in the Humanities 5**

Humanities Research Group

University of Windsor

1996



LEDW  
CIRC

© 1996 by the authors

R  
727.3  
.E96  
1996

## Canadian Cataloguing in Publication Data

Main entry under title:

Expanding health care perspectives: policy making towards the year 2000: proceedings of the workshop held at the Humanities Research Group, University of Windsor, March 31, 1995

(Working papers in the humanities 5  
Includes bibliographical references.  
ISBN 0-9697776-4-7

1. Medical care—Canada—Congresses. 2. Medical policy—Canada—Congresses. 3. Health care reform—Canada--Congresses. I. Drake, Mary Louise, 1940- II. University of Windsor. Humanities Research Group.  
III. Series.

R727.3.E96 1996 362.1'0971

C96-900356-0

**CONTENTS**

<b>PREFACE</b>	vii
<b>INTRODUCTION</b>	ix
<b>MAUREEN MULDOON</b>	
What Is It Like For You? Professional Caregiver/Patient Relationships: Communicating The Meaning Of Illness	1
<b>ANNE FORREST</b>	
Through Her Eyes: A Feminist Reconstruction of the Breast Cancer Experience	11
<b>ALAN SEARS</b>	
The Future Of Health Care: Lessons From The AIDS Movement	25
<b>CONTRIBUTORS</b>	37
<b>PARTICIPANTS</b>	39
<b>SUGGESTED FURTHER READINGS</b>	41

## PREFACE

As part of its mandate to promote interdisciplinary research and to bring the wisdom of the humanities to bear on issues of contemporary concern, the Humanities Research Group began to publish a series of Working Papers in the Humanities. The current volume is the fifth to appear.

The series is designed to present works in progress by various scholars representing a broad spectrum of disciplines, methodologies, and perspectives, all united by a focus on a single theme. Earlier volumes have presented the papers of our annual Distinguished Speaker Series, and of a conference held at the University of Windsor. The papers included in this volume were delivered as part of the Humanities Research Group's Community Seminar programme. Those seminars are an important initiative that allow members of the community to take a day to reflect on an issue of immediate relevance to both the local community and society as a whole. Discussion is promoted by the case studies or papers offered by members of the University of Windsor faculty. The opportunity to bridge the distance between town and gown, between theory and practice, in an interdisciplinary humanities setting, is important to the mission of the Humanities Research Group, to the academy and to the community. In an era of technological overload and utilitarianism the humanities still have an important role to play. It is essential as well, for the academy and humanists in particular, to recognize their social responsibility and share their insights and perspectives with those in society charged with developing and implementing policy. Such dialogue is essential and this volume is part of our contribution to it.

*Jacqueline Murray*  
*Director*  
*Humanities Research Group*



## INTRODUCTION

This era, the twentieth century, has been compared to the Golden Age of Greece. Since the turn of the century, the explosion in the discovery of new knowledge, technology, education, and social advances has been unprecedented. Who would have thought at the turn of the century and even into the fifties, that there would be men on the moon, the discovery of DNA, organ transplants, magnetic resonance imaging, jet travel, computers, and the eradication of diseases? The development of such advances and, more importantly, their almost universal availability has created a sense that everyone must have everything whether or not it is needed or whether or not it will improve their quality of life. Among the developments of this century, a real milestone is the availability of health care.

Guaranteed health care was first established in Canada by the Medical Care Act of 1966. In order for the provinces to receive financial support for the provision of such health care, they had to demonstrate that the health care plan was comprehensive, universal, portable, and publicly administered. One of these four premises that is in jeopardy today is the concept of universality. Universality represents the equal opportunity for health care for all people in Canada. Whenever the need for health care is felt, consumers want to be able to access the health care system quickly and directly. This demand for 'equality of care' is interpreted by most Canadians as a 'right' conferred by the Medical Care Act of 1966 and upheld in the Canada Health Act of 1984.

This equality of care leads most Canadians think that every other person in Canada receives identical or the same type of care. Equal opportunity means that everyone should have the same chance to receive health care. These two terms get confused when it comes to the provision of health care. Women in P.E.I. do not have the same opportunity for gynecological care as do women in Ontario. People in Northern Ontario do not have the same range of services as do people in Southern Ontario. For example, the access to care for mental illness is very limited in Northern Ontario. Locally, there are few mental health care services available for adolescents, especially adolescent males. Along with the limitations of services in various areas, is the added

aspect of the consolidation of services. Analysis of services in Windsor demonstrated that four hospitals offered duplicate services. In the new configuration, two hospitals have been allocated services for which they appear to have the more advanced facilities. System-wide cost-effectiveness of plant and services is the goal of contemporary health care programmes whether they are in the community or in institutions.

Today's economic situation is forcing the health care area to examine services, who provides care? who receives care? where is it provided? which services are required and why? Currently Windsor, Ontario is undergoing the process of reconfiguration of health care. A task force of local citizens chaired by Mary Jean Gallagher, under the aegis of the Essex County District Health Council, developed a report designed to remodel local health care delivery. The Essex County Win/Win Model — An Evolving Plan for Total Health System Reconfiguration — identified that from the consumers' and taxpayers' perspective, our local network of health and health-related social services is fragmented, uncoordinated, and wasteful.<sup>1</sup> Among other problems mentioned is the observation that services do not reflect the community's needs. What is interesting about this health care development is the fact that, although people in Windsor and in the Province of Ontario feel that this taskforce was initiated by the government, the original impetus behind reconfiguration came from the administrators of the four hospitals in Windsor. These administrators demonstrated responsibility and accountability, recognizing the need to trim health care services, eliminate duplication, be cost effective, and still deliver universal, quality health care.

Health care providers and the consumers of health care have a unique opportunity at this time in Windsor to create a quality health care system that meets the needs of the consumer and matches the expertise of the various providers. While the goal seems ideal and inarguable, it is a risky venture as it places in question cherished beliefs and values about health care.

Questions of maintaining quality and access to all forms of services arise. It shakes the foundations of territoriality, the nature and retention of experts, and the ceilings to the cost of services. Our community seminar sought to stimulate dialogue on these and other aspects of health care delivery. We questioned and examined currently held ideas of health care. Who should administer health care? How and which

---

<sup>1</sup>*The Essex County Win/Win Model: Evolving Plan for Total Health System Reconfiguration*, The Final Report of the Steering Committee on Reconfiguration (Windsor, ON: Essex County District Health Council, 1994), 24.



services should be identified? Most importantly, we bonded together to HEAR and to LISTEN to the consumers. Patients and families want to be able to control what is or is not done to and for them in the name of health care.

Though technological advances assist people to live, as well as to live longer, loss of basic humanness and compassion occurs, more frequently than health care providers like to admit, when technology dominates care. Competition for technologies amongst hospitals for purposes of economic survival has created the need for every hospital to have the most modern equipment in order to be at the forefront of health care. This competition leads to several problems. First, the patient is neglected in terms of what she/he thinks should happen. Second, hospitals in the same city attempt to have the latest and the best technology. Third, the cost of providing this standard of health care escalates. Finally, the notion that the only place to receive the best care is in the hospital dominates the health care delivery system.

Change is occurring in spite of this thinking. A sign of this change is noted in the Ontario Health Survey conducted in 1990. The Province of Ontario established the following goals:

1. Shift the emphasis to health promotion and disease prevention;
2. Foster strong and supportive families and communities;
3. Ensure a safe, high quality physical environment;
4. Increase the number of years of good health for Ontarians by reducing illness, disability, and premature death;
5. Provide accessible, affordable, appropriate health services for all.<sup>2</sup>

These goals reflect the ideas established by previous Federal Ministers of Health, Marc Lalonde and Jake Epp. Both of these ministers recommended that health care focus on the promotion of health and the prevention of illness. Mr Lalonde, in his address for the Boland Memorial Lecture, stated that the improvement of the social and physical environment and the modification of certain living habits influence the level of health and fitness.<sup>3</sup> Health promotion and prevention of illness are more important than 'curing.'

A health promotion concept places the emphasis on the person to

---

<sup>2</sup>Ontario Health Survey 1990, Premiers Council on Health, Well-being, and Social Justice, Toronto, Ministry of Health of Ontario, September 1992, viii.

<sup>3</sup>J Alex Murray, ed. *Health Care Delivery Systems in North America: The Changing Concepts*, Proceedings of the 18th Annual Seminar (Windsor, ON: Canadian American Seminar, University of Windsor, 1976), 171.



care for him/herself appropriately and for the health care provider to teach the patient how to do this. It re-introduces personal accountability and common sense into the equation of health care provision. This 'common sense' aspect of health care recognizes that the consumer/patient/client has input into the what, when, where, and how services are needed for maintaining and promoting her/his health.

This community seminar, "Expanding Health Care Perspectives: Policy Making for the Year 2000," is also asking local health care providers to recognize the role of the consumer in determining what services are needed locally and how people interpret health care information and attention.

Interestingly, this is not the first time that the University of Windsor community initiated discussion on health care. In 1976, under the auspices of the Canadian American Seminar, a conference on *Health Care Delivery Systems in North America: The Changing Concepts*, was held. That conference, reflecting the thinking of 1976, focused on the problem of having a sufficient numbers of physicians "functioning in a delivery system to bind the wounds and treat the ills of all North Americans."<sup>4</sup> Although the focus in the 90s is different, local health care providers in 1976 did suggest today's direction. Dr S Olesiuk of Windsor stated,

I appreciate the people that you have here. You have a lot of high level people speaking and there is very little input from the real individuals who deliver health care. I think that if you are going to have solution to the problems, you have to come down to the local community, . . . I think that if you have to cut down on costs, you have to put the onus and the responsibility on the individual patient and the practicing physician,<sup>5</sup>

and I would add, the practicing nurse. Another participant, Ms Ada E McEwen, National Director of VON, commented that "health teaching has always been an important aspect of all programs with emphasis on encouraging individual and family independence." She continued:

the VON has always been convinced that the home is a 'good' place to provide care to people, not because it is cheaper, although that is an important consideration, but because it allows people to be cared for in familiar surroundings which are conducive to recovery and to rehabilitation. There the services can be adjusted to the patient rather

---

<sup>4</sup>Murray, *Delivery Systems*, i.

<sup>5</sup>Ibid., 118-19.

than the patient adjusting to the rules and regulations of an institution.<sup>6</sup>

This is the crux of the present volume how to adjust the rules and regulations of local health care providers to meet the needs of the health care consumer in the reconfiguration of health care in Windsor. "The current system does not acknowledge the importance that should be placed on the views of the consumer, direct service providers, and support staff."<sup>7</sup>

In a recent segment on Peter Gzowski's *Morningside*<sup>8</sup> a group of health care experts discussed the changing provision of health care across Canada. These experts recognized the need for community involvement and recommended the importance of having health care meet the needs of the population of the area. Dr Ron Stewart, Minister of Health of Nova Scotia, stated that one way to improve the quality of care and the costs of services is to return decision making to the community. He stated that services must go to underserved areas and the "best sources in terms of what services are needed are the people on the ground." Jane Fulton, another guest, remarked that health care services should reflect local populations. Not all services will look the same everywhere in Canada. If the area has an aging population then services should reflect that population.

The adequacy of the client to identify health care needs has been well demonstrated by patients with AIDS and their families. Through their lobbying, the AIDS movement has received money for research and treatment with experimental drugs. Patients with AIDS and their families have identified the kind of care needed for themselves and others and have insisted that, that type and quality of care be given. Education and health promotion issues have also been addressed in preventing AIDS. Interested citizens have developed focus groups to deal with the needs of clients who are mentally ill, chronically ill, homeless, developmentally delayed, or addicted. In an effort to help people die in a dignified manner, with reduced pain, Hospice groups have initiated the use of palliative care regimens such as therapeutic touch, aromatherapy, massage therapy, and in-home support to reduce the stress of caring for a dying family member. More and more people are recognizing the efficacy of being treated at home. For example, an

---

<sup>6</sup>Murray, *Delivery Systems*, 142.

<sup>7</sup>Win Win Model, 76.

<sup>8</sup>*Morningside*, CBC Radio, 30 May 1995.



at-home intravenous antibiotic therapy programme, administered by a nurse, introduced in Alberta (1993) saved \$99,540 in costs, in one year alone.<sup>9</sup>

Innovation, risk taking, letting go of health care provider control over decision making, developing a health care contract with the client, encouraging health care decisions by the client and by the community will revitalize health care in Windsor. Do we, do you, have the courage to be different, to lead, to create, to provide, and to receive health care in new ways? Reconfiguration of the health care services in Windsor is an opportunity for all participants in the health care continuum (consumers, providers, agencies) to grow and to effect change by developing health care that meets the demands of our local populations whether in the social, cultural, physical, psychological, or spiritual domains.

The plenary speakers Dr M Muldoon, Dr A Sears and Dr A Forrest provided the group with various concepts surrounding health care and health.

During the discussions that followed the plenary sessions, many interesting ideas and approaches to health care evolved from the presentations by the plenary speakers. Dr Muldoon's case history stimulated the participants to identify that health care needs to move toward a more people centred wholistic model. Health is more than the absence of disease. The determinants of health include ourselves, and other factors such as a clean environment, housing, income, employment, and nutrition. It is the concept of wholeness, wellness, and the integration of body, mind, and spirit. Recognition of the importance of traditional self-care models is necessary to meet the needs of different ethnic groups. Other cultures encourage the use of home remedies and the use of practices that result in effective health care.

Empowerment of patients was another concept generated by all three plenary speakers. This concept encourages patients to be an active participant in decisions about their health care. As well, it allows patients to ask questions and to advocate for themselves. Dr Forrest's discussion of breast cancer reinforced strongly the issue of empowering women to make decisions about their health care. As well, the groups felt that it is an adjunct to care to be aware of the psychological and sociological effect that the diagnosis of breast cancer has not only on the woman herself but also on her significant others (family, friends, employer/employee).

---

<sup>9</sup>Canadian Nurses Association, *IV Antibiotic Treatment At Home* (Ottawa: Canadian Nurses Association, 1994).



Dr Sears's discussion of AIDS emphasized the relevance of community development and mobilization. His talk demonstrated the power of a consumer driven approach to AIDS and its effect on the health care establishment. The AIDS movement has demonstrated how things can be done and that we really can learn how to get our own health needs met, whatever they maybe.

The role of economics within the health care system was also recognized by the groups. A major concern expressed was that a balance in health care be available. An equal opportunity to receive the health care that the patient needs, and defines as what is needed, must be ensured. With reconfiguration health care providers must be open to change. We cannot continue to provide services as we have been doing. Through rethinking the process we will be able to provide health care that the individual has chosen and that gives the individual control in the health system and recognizes the role of the community in developing appropriate health care resources.

*Mary Louise Drake  
School of Nursing  
University of Windsor*

**WHAT IS IT LIKE FOR YOU?  
PROFESSIONAL CAREGIVER/PATIENT RELATIONSHIPS:  
COMMUNICATING THE MEANING OF ILLNESS**

**Maureen Muldoon**

Health care reform is currently in the forefront of pressing social, political and economic issues. There is the wavering hope that, in the midst of this bureaucratic turmoil and market language, all types of health care services will be available when needed. But, there is also an uncertain fear that when these services are needed, they will not be accessible.

Another aspect of contemporary health care delivery which generates frustration, anger, and perhaps, litigation, is the 'indignities' of being a patient. The person afflicted with an illness may be designated as a consumer of services, a client, or traditionally, as the patient. However, these role-descriptive terms do not capture or even suggest the meaning of illness for the person. It is not surprising, then, that those afflicted with illness are now telling their stories of what it means to them to be sick. Their self-revelations are poignant as they introduce the healthy to their inner world. This paper examines the importance of these stories for the health care professional-patient relationship. It is ethically important to attend to the experience of illness by the patient.

Current literature on professional caregiver/patient relationships characterize them along a spectrum from being a contract to something much deeper and profound. For instance, Eric Cassell describes the most skilled practitioner as one who "raises the relationship to an art, not only encouraging its growth and promoting trust and faith on the part of the patient, but negotiating between intimacy and separateness, between empathy and objectivity."<sup>1</sup> Notice that he is describing the

---

<sup>1</sup>Eric Cassell, *The Nature of Suffering and the Goals of Medicine* (New York: Oxford University Press, 1991), 79.

## 2 Maureen Muldoon

relationship from the caregiver's point of view, not the sick person's perspective.

S Kay Toombs, a philosopher and a person living with multiple sclerosis, explores the different perspectives in the physician-patient relationship in her book *The Meaning of Illness*.<sup>2</sup>

She explains that it is particularly difficult to establish a shared world of meaning between the physician and the patient because of the failure of the 'interchangeability of standpoints.' Toombs goes on to note "that the physician and the patient apprehend illness from within the context of separate worlds, each providing its own horizon of meaning."<sup>3</sup> One concept which she develops is 'focusing.' Both the patient and the physician attend to the patient's illness, but each one focuses on different aspects of the experience. The physician seeks to understand the illness in terms of particular disease states while the patient is experiencing the bodily effects and the impact on day-to-day life.

Physicians and other professional caregivers are recognized as being 'professional' because of their specialized knowledge. One goal of their education is to develop certain 'habits of mind' which create a horizon meaning and a 'system of relevances' in order to interpret 'reality.' These particular 'habits of mind' also contribute to the establishment of the culture of the profession.<sup>4</sup> Thus, the designation of 'expert think,' unique to each profession and to variations within the dominant schools of thought within each profession.

Even though medical education is changing and many physicians respond to their patients in alternate ways, it can be said that there are 'habits of mind' of the medical profession regarding the apprehension of illness. When encountering a person who claims to be ill, the physician will respond in terms of his or her training and the goals of the profession. Often, this approach means taking a medical history, establishing a diagnosis, a prognosis, and a treatment plan. In the scientific medical model, the individual is assumed to be healthy when clinical tests appear within normal ranges. Disease may be indicated when the objective tests deviate from the norm. The clinical goal is to treat the disease and alleviate the symptoms. One of the reasons that

---

<sup>2</sup>S Kay Toombs, *The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physicians and Patient* (Dordrecht, The Netherlands: Kluwer Academic Publishers, 1993). Toombs provides a phenomenological analysis of these different perspectives, considering the concepts of focusing, the natural and naturalistic attitude, temporality, and relevance.

<sup>3</sup>Ibid., 10.

<sup>4</sup>Ibid., 10-11.



this medical model is still influential is that, in many situations, it works well. The subjective reality of the patient as person is not factored in by the physician or patient in the cause of illness or the treatment.

Nursing, as a profession, also has its 'habits of mind' and 'systems of relevances.' An often cited claim is that nurses account for the 'whole person' in relationship to his or her environment. One nurse explains that:

the goal of nursing focuses on the quality of life as perceived by the person or family. The nurse guides changing health patterns that shape the quality of life, while recognizing the authority and decision making power of the person or family.<sup>5</sup>

Ideally, if this theory could be put into practice, patients would be well served. Clearly, there are many models of nursing theory which attempt to overcome the sick person's experience of being treated just as a body and acknowledge the subjective reality of the patient as person. However, these 'habits of mind' assume too much. Just as the physician and the patient find it difficult to communicate about the experience of illness because there is not a basis of a shared set of assumptions, nursing theory, even with the explicit intention of assisting the patient to make choices out of his or her unique experience of illness, does not share the same basic set of assumptions with the patient. A recent Canadian study found that in caring for critically ill patients without explicit advance directives (and often for those who do), nurses and doctors make decisions based on their own ethical, social, moral, and religious values as well as their own work experience. In addition, it was found that there was great variability in what level of care may be chosen when the caregivers were asked what they would provide to twelve hypothetical patients with different medical conditions.<sup>6</sup>

The assumption that professional caregivers are able to communicate readily with patients about illness on the basis of a shared understanding may in fact leave the patient more isolated. Toombs asserts the "unshareable characteristic about illness . . . derives from its being

---

<sup>5</sup>For an example, see Mary Jo Butler, "Family Transformation: Parse's Theory in Practice," *Nursing Science Quarterly* 1 (1988): 68-74.

<sup>6</sup>Deborah Cook et al. "Determinants in Canadian Health Care Workers of the Decision to Withdraw Life Support From the Critically Ill," *Journal of the American Medical Association* 273 (1 March 1995): 703-08.

an inner, rather than an outer, event."<sup>7</sup> There are many 'inner' effects of illness for a person. First, the person relates to her own body differently. The body is separated from the self. It is objectified. The person/self has to deal with this body which may be the source of pain and loss of function and eventually will die. Depending on the bodily disruption, the body may become an 'oppositional force' (beyond the control of the self — loss of motor function) or even a malevolent force (threatening one's dignity — loss of bladder function). The illness may cause a disruption in the day-to-day life of the person, affecting personal and social relationships and the ability to work. There is no easy access for the professional caregiver to know how the illness has affected these aspects of a person's life. As well the experience of pain by the patient is not easily shared. Elaine Scarry explains:

When one speaks about 'one's own physical pain' and about 'another's physical pain, one might almost appear to be speaking about two wholly distinct orders of events. For the person whose pain it is, it is 'effortlessly' grasped (that is, even with the most heroic effort it cannot be grasped): while for the person outside the sufferer's body, what is 'effortless' is not grasping it (it is easy to remain wholly unaware of its existence; even with the effort, one may remain in doubt about its existence or retain the astonishing freedom of denying its existence; and finally, if with the best effort of sustained attention one successfully apprehends it, the aversiveness of the 'it' one apprehends will only be a shadowy fraction of the actual 'it'.)<sup>8</sup>

In addition, illness affects the sick person's experience of time and space. The sick person has to live with two experiences of time. In order to communicate with caregivers, there is the need for the patient to communicate in outer 'objective' time. However, illness is experienced in terms of inner time. The sick person has to contend with waiting for the test results, getting through the night, and counting the hours for the next dose of pain medication. The effort it takes to live through the inner time remains a private and isolated task for the patient.

Orientation to time changes with certain illnesses. Goals set when healthy may no longer be attainable. A person facing a life threatening illness may feel that she has lost their future altogether. Or time may

---

<sup>7</sup>Toombs, *The Meaning of Illness*, 23.

<sup>8</sup>Elaine Scarry, *The Body in Pain* (New York: Oxford University Press, 1985), 4.



expand, as previously simple tasks such as getting dressed or eating may take hours to accomplish.

Illness may also alter the sense of space. A person orients themselves in terms of the space around them. However, when a person is sick, his functional space may involve lying in a hospital bed or trying to manoeuvre in a house which has been altered to be wheelchair accessible. Instead of standing face to face with others, the sick person must look up from a sitting or lying position. Toombs notes:

To be able to 'stand on one's own two feet' is of more figurative significance. Verticality is directly related to autonomy. Just as the infant's sense of autonomy and independence are enhanced by the development of the ability to maintain an upright posture and 'sally forth' into the world unaided, so there is a corresponding loss of autonomy which accompanies the loss of uprightness.<sup>9</sup>

The inability to stand vertical leaves the person with the feeling of helplessness and dependency.

Eric Cassell distinguishes between the pain and the suffering caused by the illness. He states that one suffers, not necessarily when one is in pain, but when there is a threat to the integrity or intactness of the person. Suffering can occur in any aspect of the self. Suffering is alleviated when the threat is lessened. He goes on to note that usually the patient and the general public believe that health care should be about relieving suffering, but little preparation and education takes place to help health care professionals sort out what suffering entails beyond physical pain.<sup>10</sup>

### *Working Toward a Shared World of Meaning*

What can the health care professional do with the patient to address the different standpoints and 'habits of mind?'

1. *Recognize that the patient has a lived experience of illness which is different from the medical description of the illness.*

The illness is experienced as a loss for the patient: a loss of wholeness, certainty, control, and freedom. The taken for grantedness of everyday life is gone. The meaning of illness can only be determined

---

<sup>9</sup>Toombs, *The Meaning of Illness*, 65.

<sup>10</sup>Cassell, *The Nature of Suffering*, 33.



by the person afflicted with the illness.

Toombs asserts that the goal of medicine must shift from curing to healing. It is this change in focus which takes the patient's experience of illness seriously. When healing takes place, there is a restoration or preservation of 'a sense of equanimity and personal integrity' in the encounter with illness.<sup>11</sup>

## 2. Acknowledge one's own professional caregiver narrative.

Larry and Sandra Churchill describe narration as the "forward movement of description of actions and events which make possible the backward action of self-understanding."<sup>12</sup> The narrative is not an 'objective' factual description of events, but rather an interpretation of those events in a way that is meaningful to the narrator. Storytelling is both self-revelation and a connection to our common human experience. Stories draw the listener into other people's lives and enhance the capacity to understand other aspects of the human drama both currently and historically.

Often, when the importance of narratives are acknowledged in medicine, it usually refers to the patient's narrative. However, professional caregiver narratives are important as well. Patricia Benner describes how narratives, especially those that preserve practices and traditions, contribute to the ethical practice of the profession by engaging the caregiver personally with the patient.<sup>13</sup> Examining nursing narratives, Benner identifies two major types of narrative themes which are operative in the fostering caring nursing practice. Constitutive or sustaining narratives present situations with insight into what it is to be a nurse. These narratives preserve and call to memory the significance of the work. The particular narrative usually echoes in some way the larger cultural narrative, for instance, the fundamental role of caring in nursing. The narrative may serve as a paradigmatic case which is illuminating and sustaining as other clinical situations are encountered.<sup>14</sup>

---

<sup>11</sup>S Kay Toombs, "Chronic Illness and the Goals of Medicine," *Second Opinion* 21, no. 1 (July 1995): 13.

<sup>12</sup>Larry Churchill and Sandra Churchill, "Storytelling in Medical Arenas: The Art of Self-Determination," *Literature and Medicine* 1 (1982): 73.

<sup>13</sup>Patricia Benner, "The Role of Experience, Narrative, and Community in Skilled Ethical Comportment," *Advance Nursing Science* 14, no. 2 (1991): 1-21.

<sup>14</sup>*Ibid.*, 5-7. Benner explores these themes by presenting a narrative account of a nurse, Kimberly Baird, who is responsible for the care of a young boy of

A second type of narrative theme is that of learning, which Benner explores in terms of sub-themes. Narratives about being open to experience reveal that the caregiver is personally engaged with the patient. She knows that the patient is more than a label and that there may be something to learn even from failure. Narratives of learning also include the appropriate relational skills for the professional. The narratives of disillusionment are those stories about limits with regard to knowledge, control, human capacities, and understanding and policies and rules. Narratives about facing death are shared experiences which help the professional caregiver and the wider community to confront suffering and death. Benner describes liberation narratives as a broad range of stories which may deal with issues concerning inter-professional relationships and status inequity to those stories about moving beyond biases and misunderstandings. The stories/narratives inform the nurse's understanding of her role and what it means to be a person of integrity within that role. Benner asserts that "the narrative memory of the actual concrete event is taken up in embodied know-how and comportment, complete with emotional responses to situations."<sup>15</sup> Stories illuminate for professionals the meaning of care, not in a formal way, but by showing what caring means in practice.

### 3. *Seek out the clinical narrative of the patient.*

The clinical narrative is the story of the illness as told by the patient. It includes the story of how the patient discovered the illness, the point at which the patient sought out health care, the patient's explanations, and interpretations of what is happening. The patient explains what is significant about the illness and how it is having an impact on everyday life. It details how the illness has disrupted life. For example, consider the experience of two people: one man afflicted with metastatic prostate cancer and another man with Amyotrophic Lateral Sclerosis (ALS).

Anatole Broyard, a writer for the *New York Times*

Just as a novelist turns his anxiety into a story in order to be able to control it to a degree, so a sick person can make a story, a narrative, out of his illness as a way of trying to detoxify it. I saw my illness as a visit to a disturbed country, rather like contemporary China. I

---

an Amish family who had been injured on the farm.

<sup>15</sup>Benner, "The Role of Experience," 16.



imagined it as a love affair with a demented woman who demanded things I have never done before . . . Having cancer was like moving from a cozy Dickinson house crammed with antiques, deep sofas, snug corners, and fireplaces to a brand-new one that was all windows, skylights, and tubular furniture . . . If I were to demystify or deconstruct my cancer, I might find that there is no absolute diagnosis, no single agreed upon text, but only the interpretation each doctor and each patient makes.<sup>16</sup>

Dennis Kaye, a man who became known as the Incredible Shrinking Man on a CBC radio show expresses a very different experience:

Am I getting out just in time? I think not. Should I feel grateful for having been blessed with a fatal disease? I think not. Must I apologize for being happy? I think not. Sometimes I wish I could just jump up out of my chair, wipe the spit from my chin and yell at the top of my under-inflated lungs, 'I'm happy as hell and I'm not going to take it any more! I am invalid, hear me roar. I twitch, therefore I am . . .'

There is still love in our home, often joy, and rarely a day without laughter. All things considered, when I put ALS up against the things in life that really count, it doesn't stand a chance.<sup>17</sup>

It is only through the narrative that the caregiver begins to hear what the illness means to the afflicted person. The aesthetics of the illness, personally and culturally, for that particular person may be revealed. For instance, some illnesses may be tolerable because the family may have some previous experience of it, while other illnesses are considered 'a death sentence,' 'dirty' or evil because of specific cultural connotations.

The clinical narrative can be distinguished from the medical history which seeks to establish the onset of symptoms, the diagnosis and options for treatment, and other relevant medical conditions. A person can be dehumanized by a medical history if the who is replaced by a what, for example, the 'gall stones case.'<sup>18</sup>

The narrative can be elicited by such questions as: What has this illness been like for you? What is your understanding of this illness in terms the onset of symptoms? How have you experienced the treatment? What are your fears about this treatment? Or illness? Such

---

<sup>16</sup>Anatole Boyard, *Intoxicated by My Illness: And Other Writings on Life and Death* (New York: Fawcett Columbine, 1992), 20-21.

<sup>17</sup>Kaye, *Laugh, I Thought I'd Die* (Toronto: Viking, 1993), 220-21.

<sup>18</sup>Churchill and Churchill, "Storytelling in Medical Arenas," 77.



questions help the professional caregiver have some insight into what is actually happening to the patient and adjust treatment appropriately. The clinical narrative helps the professional caregivers to determine what the patient wants. The patient goals can be identified and they may be different than established treatment goals. It is important for the professional caregiver to know if the care being administered is healing the patient or is, in fact, a source of suffering. If it is, other options for care may be explored that may be less burdensome. In some situations, the health professional can act as an 'arbitrator of meaning,' assisting the patient to change an inappropriate interpretation of the situation. For instance, a person newly diagnosed with cancer may only have knowledge of the disease offered in the popular media. The patient may have many fears about what will happen to them. The sensitive professional may be able to present information about the disease which would lessen the distress for the patient. If the patient can tell his story and the patient's meanings are understood, then, in response, it is possible for the practitioner to share her explanatory model of illness with the patient and have the caregiver's meanings understood as well.

#### *The Ethical Implication of Taking the Clinical Narrative Seriously*

Patricia Benner argues that it is necessary for professional caregivers to attend to the clinical narrative in order to care for the patient in an ethical manner. There are a growing number of ethicists who share this view.

Howard Brody explains how narrative ethics enhance current bioethical approaches. He notes that there are different approaches to doing ethics, offering various frameworks of formal reasoning.<sup>19</sup> Narrative ethics attempt to determine a good moral outcome in a particular case by learning the detailed story about the case. The moral character and integrity of the stakeholders are critical components in the assessment. The analysis requires interpretation of what the facts mean within the situation. Reasoning may be by analogy, that is, by noting similarities and dissimilarities to other cases. The emotional response evoked by the story is acknowledged as an aid to ethical

---

<sup>19</sup>Philosophy and theology have a rich history of discourse regarding these formal approaches. Most bioethics textbooks develop the deontological approach, referring to principles, or a utilitarian approach, assessing the consequences of the action.

insight. This empathy is not considered a loss of objectivity.<sup>20</sup>

Referring to the dominant principles of bioethics, it is clear that it is in the patient's clinical narrative, as well as the professional caregiver's narrative, that the principles of autonomy, beneficence, and non-maleficence take shape. Without a narrative structure, they remain abstract. It is through the clinical narrative that the professional caregiver can know if the person is autonomous or coerced; what course of treatment will actually benefit this patient, meet the patient's goals; and what constitutes harm for the patient.

In conclusion, professional caregivers cannot assume that they have easy access to the lived experience of those who are ill. Professional 'habits of mind,' 'systems of relevances,' and the political and economic dynamics of health care contribute to the creation of a world view which is very different from a person who is contending with a life-disrupting illness. One important approach to addressing this difficulty is learning to take professional caregiver and clinical (patient) narratives seriously. This author argues that these narratives are critical in ethical analysis.

---

<sup>20</sup>Howard Brody, "The Four Principles and Narrative Ethics," in *Principles of Health Care Ethics*, ed. Raanan Gillon (Chichester: John Wiley and Sons, 1994), 207-15.

**THROUGH HER EYES:  
A FEMINIST RECONSTRUCTION OF THE  
BREAST CANCER EXPERIENCE**

**Anne Forrest<sup>1</sup>**

I dedicate this paper to the raging spirit of Kathleen Martindale: leftist, feminist, educator, lesbian. Kathleen was killed by breast cancer on February 17, 1995, one of 5,400 women in Canada who will die of breast cancer in this year.<sup>2</sup>

In this presentation, I use the experiences and insights of women afflicted with breast cancer to illustrate how our understanding of breast cancer reaffirms, yet draws into question, cultural stereotypes of womanhood. I argue that what we 'know,' that is to say, what we believe to be true about breast cancer as disease and lived experience is profoundly shaped by the fact that women are the primary sufferers. Adopting the metaphor of women's bodies as a site of struggle, I explore three themes which shape the experience of breast cancer as disease.

First, I will examine how our knowledge of the causes of breast cancer is shaped by what the medical community believes to be true about women and their bodies, as much as by the scientific study and observation of the disease. The medical and psycho-social understanding of this disease is rooted in stereotypes and often assumes that women's bodies are inevitably or naturally defective. It often focuses on confirming these stereotypes rather than coming to grips with the skyrocketing incidence of breast cancer and providing sound, health-promoting strategies for prevention and avoidance of recurrence. This section is called, "Who Is To Blame?"

---

<sup>1</sup>The author wishes to acknowledge the help of Rena Isenberg in writing this paper.

<sup>2</sup>National Cancer Institute of Canada, *Canadian Cancer Statistics 1996* (Toronto: Statistics Canada, 1995).



definition of women's bodies — breasts in particular — as sex objects means that breast cancer has the potential to 'disfigure' and defeminize women. Women with breast cancer inevitably subvert cultural stereotypes of femininity/beauty even as they struggle to conform. I argue that our society's fetishistic definition of women's bodies as sexual leads to an understanding of the experience of mastectomy and, to a lesser extent, chemotherapy as, first and foremost, threats to a woman's femininity, even though the women themselves are more likely to focus their energy and anxiety on the elemental issues of living and dying. I call this section, "Whose Breast Is It?"

Third, in response to the question, "Who Is in Control?" I explore how diagnostic and treatment protocols assume that women are compliant, 'good girl' patients, even as the lived reality of incomplete information, limited options, and invasive treatments pushes women with breast cancer to challenge the medical establishment on which they must rely.

Anticipating that these claims may seem improbable, I begin by offering a similarly structured argument as a guide to my reasoning. In her article entitled, "Sperm Meets Egg: The Story of a Scientific Romance," anthropologist Emily Martin demonstrates that "the picture of egg and sperm drawn in popular as well as scientific accounts of reproductive biology relies on stereotypes central to our cultural definitions of male and female."<sup>3</sup> Martin shows how scientific descriptions of the fertilization process have both assumed and affirmed the traditional (aggressive and assertive) boy meets (passive and compliant) girl story. For many years, she notes, biology and medical texts characterized the egg in the story as a damsel in distress or a Sleeping Beauty awaiting her prince's charmed kiss. Even the updated editions of these texts continue to employ imagery which relies on traditional gender stereotypes. In the revised version of the romance, the egg is likely to be cast in the role of wicked and entrapping *femme fatale*. (The sperm, by contrast, has been consistently portrayed as the heroic male struggling to do his duty.)

Here, we find evidence that popular notions of what it means to be female and male in this society are so deeply embedded, so commonsensical, so invisible, that detached, scientific minds imbue microscopic bits of matter with human personality. However, the importance of this fairy tale is not that scientists are foolish sexists, rather, it lies in the unconscious use of a way of understanding and interpreting scientific

---

<sup>3</sup>Emily Martin, "Sperm Meets Egg: The Story of a Scientific Romance," *Orgyn* 3 (1994): 7.

evidence which first presumes, then proceeds to prove certain biological 'facts.' In this case, the sperm and the egg story induces the reader to accept as *fact* the commonly held *belief* that men, by nature, are aggressive and assertive while women are 'naturally' passive and compliant. The consequences for women are obvious and severe.

And so it is for breast cancer, I argue. Here, too, presumption blends into science.

### *Who Is To Blame?*

In her cancer journal, the poet Audre Lorde wrote, "I had grown angry at my right breast because I felt as if it had in some unexpected way betrayed me, as if it had become already separate from me and had turned against me by creating this tumour which might be malignant."<sup>4</sup> The threat of bodily betrayal, such as Audre Lorde experienced, is a common theme in cancer narratives. Many women write as though their breasts are the enemy. "Get them off me," one woman pleaded with her surgeon. It was liking have "two loaded revolvers pointed at my chest," another recounts.<sup>5</sup> "Did I mourn for my breasts?" my friend Kathleen asked herself. "No, not exactly," she wrote, "I thought they were killing me."<sup>6</sup>

Information on the causes and prevention of breast cancer encourages women to identify their bodies as the source of their misery. "Are you over fifty?" the pamphlets ask. "Have a mother or sister with breast cancer?" "Never had a child?" "Started your period before age twelve?" "Menopause after age fifty?" These are the risk factors which medical science associates with breast cancer.

This message fits well within a culture that sees women's bodies as defective and troublesome. Every day, women risk being exposed and humiliated by their bodies: hips/waist/thighs that are too big; hair that persists in growing in the wrong place; sexual desires that lead to untold consequences.

Women's bodies are constantly threatening to veer out of control. In the case of breast cancer, the problem, we are told, is too much of the female hormone, oestrogen. The growing incidence of breast cancer,

---

<sup>4</sup>Audre Lorde, *The Cancer Journal*, 2d ed. (San Francisco: Spinsters/Aunt Lute, 1980), 33.

<sup>5</sup>Robin Morgan, "The Politics of Breast Cancer," *Ms* 3, no.6 (1993): 39.

<sup>6</sup>Kathleen Martindale, "My (Lesbian) Breast Cancer Story: Can I Get a Witness?" in *Resist: Essays Against a Homophobic Culture*, eds. Mona Oikawa, Dionne Falconer and Ann Decter (Toronto: Women's Press, 1994), 150.



according to one researcher, results from the modern woman's 'incessant ovulation.' Earlier onset of menstruation coupled with fewer children — one or two instead of eight or nine — cause an 'excess' of menstrual cycles, he argues.<sup>7</sup> It's not 'normal' for women to ovulate four hundred times over their lifetimes, says Montreal's most prominent breast cancer specialist.<sup>8</sup>

There is less science here than women have a right to expect. By targeting the production of oestrogen as the cause of breast cancer, the medical community pathologizes the natural functioning of women's bodies. According to Samuel Epstein, an expert in occupational and environmental medicine, cancer specialists remain "myopically fixated on obsolete 'blame-the-victim' theories of breast cancer causation."<sup>9</sup> Rather than an open-ended inquiry, researchers have latched on to the limiting assumption that women's bodies are naturally disease-producing. As a result, other possible causes, most notably environmental contaminants and diet, are ignored by all but a few.

The fixation on women's bodies as the source of the disease ignores the fact that seventy to eighty percent of breast cancers are 'unexplained,' that is, seven or eight out of ten women who develop breast cancer have none of the known risk factors, except age.<sup>10</sup> We know, as well, that one in ten women in North America — some say one in nine — can expect to develop breast cancer during their lifetime. Seventeen thousand new cases in Canada each year — an epidemic by any standard — and yet women are told only that their bodies produce too much oestrogen or that breast cancer runs in their families.

This woman-blaming approach to understanding breast cancer is compounded by the message that early detection is almost as good as a cure.<sup>11</sup> You've seen the ads: "Do breast self-exams." "Have regular mammograms." "See your doctor at the first sign of a lump." "Breast cancer can be cured!"

Breast self-examination and regular mammograms are touted as life-savers, implying that women who fail to 'look after themselves' are the

<sup>7</sup>Morgan, "The Politics of Breast Cancer," 43.

<sup>8</sup>Sharon Batt, *Patient No More: The Politics of Breast Cancer* (Charlottetown, PEI: Gynery Books, 1994), 112.

<sup>9</sup>Morgan, "The Politics of Breast Cancer," 54.

<sup>10</sup>Batt, *Patient No More*, 198.

<sup>11</sup>"When breast cancer is discovered early and treated early, the chances for recovery are good!" Canadian Cancer Society, "Information about Breast Health," 1991.



cause of their own illness. Yet, breast self-examination is of unknown usefulness. There has never been a study that shows that it reduces the death rate. But this should not be surprising: a breast lump large enough to be palpable is already ten years old.<sup>12</sup> So much for the benefits of early detection.

"The standard line is that women feel empowered by self-exams," says Susan Love, a surgeon and breast cancer specialist, "but that's not my experience . . . We use it to put the blame on women." "By pushing BSE so hard," she continues, "we've alienated many women from their bodies — they're taught to do it like a search-and-destroy mission, like their breast is the enemy that will do them in."<sup>13</sup>

The facts about mammograms are no more encouraging. The most enthusiastic adherents to the breast screening programme are women under the age of fifty;<sup>14</sup> yet, we know that mammograms are an unreliable diagnostic tool for pre-menopausal women whose relatively dense and fibrous breast tissue can obscure, or even resemble, tumours. For women under fifty, the proportion of breast lumps incorrectly identified as likely to be cancerous — in which case, the *lump* may be benign but the overall experience terrifying — is a startling thirty-eight percent. Even more worrying is the risk of false negatives and the accompanying false sense of security: If mammograms were given "to every woman in her forties who had breast cancer too small to feel, nearly forty out of one hundred cancers would be missed."<sup>15</sup> For these reasons, *Ms* magazine advises pre-menopausal women to avoid mammography except to evaluate suspicious lumps detected by other means.

For women over fifty, a group for whom regular mammograms are recommended by the medical community and the Canadian Cancer Society, a single mammogram fails to detect cancer thirteen percent of the time.

My intent, here, is not to discourage women from performing breast self-examination or having mammograms; rather, my purpose is to emphasize that early detection is *not* prevention. How to *avoid* the disease is what women want to know for themselves, their daughters, and their nieces. What we are offered instead is the possibility of early detection, high tech interventions, and hope of a cure. Moreover, the

---

<sup>12</sup>Batt, *Patient No More*, 59.

<sup>13</sup>Morgan, "The Politics of Breast Cancer," 65.

<sup>14</sup>Batt, *Patient No More*, 40.

<sup>15</sup>Morgan, "The Politics of Breast Cancer," 60.

widely accepted understanding of breast cancer as caused by women's bodies 'gone wrong' encourages researchers to look for ways to alter and 'fix' what is defective. Thus, we find that vast sums of money and ingenuity are being directed to research, the outcome of which is to 're-engineer' women's endocrine system.

The controversial tamoxifen trials are part of this enterprise. Tamoxifen is a synthetic hormone that inhibits the natural production of oestrogen. Because it has proven beneficial to certain groups of women (notably women over the age of fifty whose tumours were classified as oestrogen dependent), researchers have begun testing tamoxifen — an expensive drug with known adverse health effects — on healthy women with an elevated, that is to say, a two percent, risk of developing breast cancer within five years.<sup>16</sup> Adrian Fugh-Berman, a physician with the National Women's Health Network in the US, believes these trials herald a new era in preventive medicine. In her words, "Where previously we battled external sources of harm, we have now turned our sights towards internal enemies. The war against normal physiology has begun."<sup>17</sup>

In the meantime, nothing much is being said or done about the contaminants in our food, water, and air. Despite numerous examples of site-specific, breast cancer 'hot spots' such as Montreal and Long Island, New York, only a few studies explore the possible causal connections between exposure to chemicals and breast cancer. Most hopeful from these is the hypothesis — not yet proven — that fat-soluble chemicals such as chlorine compounds mimic or amplify the cancer-causing effects of oestrogen.

These kinds of studies, which look for risk factors outside of women's bodies, may lead to prevention strategies that will save women's lives; whereas, three decades of conventional cancer research has not slowed the death toll.<sup>18</sup> The medical community must set aside assumptions that categorize women's bodies as inherently defective. Women are not at fault; we're at risk.<sup>19</sup>

---

<sup>16</sup>Batt, *Patient No More*, 198.

<sup>17</sup>Ibid., 195.

<sup>18</sup>Ibid., 192.

<sup>19</sup>Morgan, "The Politics of Breast Cancer," 45.



*Whose Breast Is It?*

Descriptions of the experience of mastectomy — still the most common treatment for women with breast cancer — are often agonizing accounts of body hatred that persists for months, occasionally years, after the surgery. Some women talk of being 'repulsed' by their new body image. They describe themselves as 'mutilated' and 'deformed'; they cannot look at or touch themselves; they feel less attractive, less sexy. Anecdotal evidence suggests that breast cancer patients are anxious about their physical appearance and their worth as women. In one instance, a woman searched for months for a breast form with just the right nipple.<sup>20</sup> Another reported that she solved the problem of having only one breast by wearing her bra to bed.<sup>21</sup>

The socialization of women places great emphasis on the importance of the body as sex object. It is women's role to be viewed, admired, and judged. From puberty onwards, breasts are central to that project. Breasts define who women are in this culture. They are the markers of our femininity; the outward sign that we conform to the social expectations of what it means to be a woman. Even though we have almost no control over breast size, this does not prevent us from worrying, being ashamed, being proud if we feel — or others make us feel — that our breasts are too small, too large, or just right. Watching our breasts grow and develop is closely associated with the process of coming to terms with, and taking on, the responsibilities of adult women in this society — as sex objects, lovers, and mothers.

So, when we begin to look at the literature on breast cancer, it does not seem surprising to find that a great deal of attention is focused on the 'disfiguring' aspects of breast surgery or to see the amount of effort and emphasis devoted to the subject of breast reconstruction to re-establish a woman's outer (unchanged, apparently 'healthy' and 'normal') appearance. The medical and scientific community has rallied around this view of mastectomy as profoundly disruptive to a woman's sense of self. Many studies are predicated on the hypothesis that "the fundamental female role is seriously threatened by breast cancer."<sup>22</sup> Breast cancer is generally thought to be a "particularly catastrophic

---

<sup>20</sup>Betty Rollin, *First, You Cry* (New York: Signet, 1976).

<sup>21</sup>Beth E Meyerowitz, Shelly Chaiken, and Laura K Clark, "Sex Roles and Culture: Social and Personal Reactions to Breast Cancer," in *Women with Disabilities: Essays in Psychology, Culture, and Politics*, eds. Michelle Fine and Adrienne Asch (Philadelphia: Temple University Press, 1988), 83.

<sup>22</sup>*Ibid.*, 75.



experience" that entails "special problems associated with adjustment."<sup>23</sup> We learn, for example, that breast cancer patients are referred for psychiatric counselling at a significantly higher rate than other cancer patients.<sup>24</sup>

The prevailing view is that women with breast cancer wish to — or, at the very least, ought to — hide the 'disfiguring' consequences of the disease. Thus, we can observe the popularity of reconstructive surgery, breast forms, wigs, and the "Look Good . . . Feel Better" campaign sponsored by the cosmetics industry<sup>25</sup> that teaches women how to mask the enervating effects of the disease and its cures.

As in many other areas of women's experience, however, it is important to ask whether this is really how most women feel, or do we accept this description as true because of the assumptions that most of us (including women) bring to the subject and take for granted. There is considerable evidence that the push towards understanding the loss of a breast as the major trauma in breast cancer arises from a "tendency to draw conclusions that may be founded more in stereotypes of women than in sound data."<sup>26</sup> To put it somewhat more colloquially, we need to ask whose script this really is.

Interviews of women with breast cancer suggest that the socially constructed choice between life and femininity is more laid on than truly felt. There is little empirical evidence "to support either the primacy of body image concerns for most breast cancer patients or the psychological importance of helping women 'look feminine' as quickly as possible." In one study, only six percent of breast cancer patients thought the breast was a uniquely sensitive or troubling site for cancer.<sup>27</sup> What heightened their levels of distress were changes in their health, not changes in their physical appearance.<sup>28</sup> Other studies have shown similar results: breast loss was *not* the primary cause of psychological problems experienced by women with breast cancer.<sup>29</sup>

What *are* the important concerns? 'Future health' was overwhelm-

<sup>23</sup>Meyerowitz, "Sex Roles and Culture," 79.

<sup>24</sup>Ibid., 80.

<sup>25</sup>See, for example, "Look Good . . . Feel Better," *Canadian Images* (Summer 1994), 5Opp insert; and Batt, *Patient No More*, 228-29.

<sup>26</sup>Meyerowitz, "Sex Roles and Culture," 76.

<sup>27</sup>Ibid., 81.

<sup>28</sup>Ibid., 84.

<sup>29</sup>Ibid., 80.

ingly chosen ahead of changes in physical appearance as the central concern of women with breast cancer<sup>30</sup> even as their friends and loved ones incorrectly assumed that breast loss, rather than the cancer, was the sufferer's primary concern. Based on responses from breast cancer patients and from disease-free men and women, one researcher identified three perspectives:

[Those of] men (who distinguish cancer from breast cancer quite strongly, and focus on breast loss); [those of] women (who make less of a distinction, and emphasize breast loss less); and [those of] women with breast cancer (who made a distinction between breast cancer and cancer at other sites, but who do so mainly on a medical basis, and who feel that breast loss is a matter of secondary concern).<sup>31</sup>

Many women's cancer stories tell how the conventions of womanhood are enforced by others even when the woman, herself, is struggling to build a new physical identity. Audre Lorde, seeing her surgeon after her mastectomy, was told that she should wear her prosthesis because without it she lowered morale in the office.<sup>32</sup> And there is Barbara Rosenblum who, sick from many weeks of chemotherapy, dutifully donned a wig at her mother's insistence.<sup>33</sup> And Darlene Betteley, who rejected the idea of wearing prostheses after her double mastectomy. She was 'fired' from her position as a Reach for Recovery volunteer for the Canadian Cancer Society.<sup>34</sup> "The real truth," Audre Lorde wrote, "is that certain other people feel better with that lump stuck into *my* bra, because they do not have to deal with me nor themselves in terms of mortality nor in terms of difference."<sup>35</sup>

The intertwining of personal and social pressures makes it difficult for women with breast cancer to sort out whose body it is. Most of us have been programmed to view our bodies only in terms of how they look and feel to others, rather than how they feel to ourselves.<sup>36</sup> Having been told she was bad for office morale, Audre Lorde realized that this

---

<sup>30</sup>Meyerowitz, "Sex Roles and Culture," 81.

<sup>31</sup>Ibid., 83.

<sup>32</sup>Lorde, *The Cancer Journal*, 59.

<sup>33</sup>Sandra Butler and Barbara Rosenblum, *Cancer in Two Voices* (San Francisco: Spinsters Book Company, 1991), 113.

<sup>34</sup>Batt, *Patient No More*, 224-27.

<sup>35</sup>Lorde, *The Cancer Journal*, 64.

<sup>36</sup>Ibid., 64.



attitude towards breast prostheses was an index of "society's attitudes towards women in general as decoration and externally defined sex object."<sup>37</sup> The emphasis on looking normal, Lorde argued, reduced the experience of breast cancer to a cosmetic crisis. For her, the challenge was clear: "either I would love my body one-breasted now, or remain forever alien to my self."<sup>38</sup>

The sensibility of "Look Good . . . Feel Better" threatens women's ability to see themselves as they are. To look as 'normal' as possible denies what is happening to the body,; disguises the fact that it refuses to conform to the feminine script,; and encourages women to disown their 'imperfect' selves. In Audre Lorde's view,

The emphasis upon wearing a prosthesis is a way of avoiding having women come to terms with their own pain and loss, and thereby, with their own strength . . . When other one-breasted women hide behind the mask of prosthesis or the dangerous fantasy of reconstruction, I find little support in the broader female environment for my rejection of what feels like a cosmetic sham . . . I believe that socially sanctioned prosthesis is merely another way of keeping women with breast cancer silent and separate from each other.<sup>39</sup>

What good are these replacement parts to women? In other amputations, with other prosthetic devices, function is the main point of their existence.<sup>40</sup> Neither a breast form nor a reconstructed breast is functional: neither helps a woman perform daily tasks; neither offers her any sensation or feeling. The recreated breast is 'functional' only if we accept that looking 'normal,' looking 'feminine' is a central, daily task for women. Audre Lorde wrote:

When I mourn my right breast it is not the appearance of it I mourn, but the feeling and the fact. But where the superficial is supreme, the idea that a woman can be beautiful and one-breasted is considered depraved, or at best, bizarre, a threat to 'morale.'<sup>41</sup>

---

<sup>37</sup>Lorde, *The Cancer Journal*, 60.

<sup>38</sup>Ibid., 44.

<sup>39</sup>Ibid., 49, 16.

<sup>40</sup>Ibid., 63.

<sup>41</sup>Ibid., 65.

*Who Is In Control?*

The experience of breast cancer leaves many women feeling alienated from their bodies and estranged from their treatment 'team.' Sharon Batt, a journalist and breast cancer activist, explains:

We are labelled 'patients.' We are thrust . . . into a medical system governed by undisclosed rules. Here, 'compliance' gains approval. Physicians speak to us in the private jargon of medical science, or with an infantilizing 'there, there dear' paternalism.<sup>42</sup>

Even when the physician's words are comprehensible, their meaning and importance can be elusive. Told that her lymph nodes must be removed, Sharon Batt realized that she didn't know what lymph nodes were exactly, but thought she might want to keep hers. Was the operation risky? Batt asked. It could leave your arm paralysed, the surgeon replied. "Permanently?" she gasped. "Perhaps permanently," was all he was willing to say.<sup>43</sup>

This is not an unusual story. In the name of full disclosure, oncologists and surgeons often convey important information in a form that is both confusing and frightening for the patient. Time and again, women report that they are offered choices without real alternatives. Betty Rollin, a sharp and tough TV personality decided that her surgeon's suggestions sounded reasonable enough. "Anyway, what did I know?" she asked herself. "I had checked out his reputation and it was good. I had to trust him."<sup>44</sup> My friend, Kathleen, found herself in a similar predicament. "Why, then, did I do it?" she asked after recounting the horrors of radiation and chemotherapy. "I felt I had no alternative," was her response.<sup>45</sup>

Health-care professionals speak of patient empowerment and consumer choice when, in fact, all of the important decisions have already been made. It is thin "choice" indeed to decide whether or not to have some combination of surgery, radiation, and chemotherapy because these are the only treatments on offer. The treatment protocol dictates the next move; the woman's only choice is to proceed or not. The issue seems stark: Do you want to be cured or don't you?

---

<sup>42</sup>Batt, *Patient No More*, 287.

<sup>43</sup>Ibid., 9.

<sup>44</sup>Rollin, *First You Cry*, 58.

<sup>45</sup>Martindale, "My (Lesbian) Breast Cancer Story," 141.



Throughout the ordeal compliance is expected. Sharon Batt and my friend Kathleen were labelled "resistors" when they insisted on more information than the system was used to providing.<sup>46</sup>

Breast cancer is commonly experienced by women as men in control . . . of everything except the emotional burden of the disease. On hearing the news, Betty Rollin fainted, whereupon her surgeon left the room. Coming to, she overheard him say, "You never know about these things. Her doctor said she could take it . . . Everybody wants you to be honest . . . and look what happens."<sup>47</sup>

There is nothing soft, that is to say, feminine about cancer treatments. It's all 'big guns' and high tech: yet another war on women in which medical weaponry is trained to search and destroy female bodies. Both radiation and chemotherapy are domestic applications of war technologies and military descriptions of their effectiveness are commonplace. The cancer is 'bombarded,' there are 'mop-up' operations and strategy debates: Are a few big hits better than many smaller ones? Is it better to attack in the morning or late in the day? Should we take the offensive before serious trouble develops, or keep 'the big guns' as a last resort?<sup>48</sup>

There is little interest in, even tolerance of, 'softer' treatments that do not invade and sicken the body. Sharon Batt describes what she believes is the oncologist's "tumour-centred view of the world."<sup>49</sup> Like most women, Batt was not 'sick' when she was diagnosed with breast cancer — just the contrary, she was on a month-long bicycle tour of France when she discovered the lump. Batt became 'sick' only when she started treatment. She suffered all the classic side-effects: hair loss, nausea, deep fatigue, and the early onset of menopause.

The price of adjuvant radiation and chemotherapy — more and more, the standard treatment after surgery — is women's good health, a commodity the cancer community systematically undervalues, Batt argues. "For me, good health was a precious resource I wanted to guard; for [the oncologist], it was a signal I could withstand greater devastation."<sup>50</sup>

The choice between good health now and more months of life later

<sup>46</sup>Batt, *Patient No More*, 9-10; Martindale, "My (Lesbian) Breast Cancer Story," 140.

<sup>47</sup>Rollin, *First, You Cry*, 36.

<sup>48</sup>Batt, *Patient No More*, 93.

<sup>49</sup>*Ibid.*, 106.

<sup>50</sup>*Ibid.*, 99.

on is profoundly unsettling. But having embarked on the project there is no turning back. Kathleen described the need to psych herself up for her bi-weekly self-poisoning with nitrogen mustard tablets. She wrote:

I'd meditate before taking them. I never lost the feeling of profound conflict about what I was doing to my self. Of course, you don't know whether chemotherapy has worked until you have a recurrence, then, as with the other cancer treatments, you know it hasn't.<sup>51</sup>

Oncologists typically define quality of life more narrowly than do patients. Few physicians think to ask what breast cancer means to their patients. Were they to do so, they might realize that 'no treatment' is a real alternative for some women, not evidence of craziness or blind rejection of the benefits of modern medicine, as is often thought.

The demand for 'softer' treatments — treatments that do not invade and sicken — is one measure of the growing determination of women with breast cancer to assert control over what is happening to their bodies. In many ways, women with breast cancer are resisting the 'good girl' rôle that has forever been theirs. The willingness to adopt a new diet, the popularity of the cancer narrative, the religious quest, all bear witness to a woman's need to understand and take ownership of the breast cancer experience. For their efforts, women are more likely to be belittled than praised by a medical community that gives little credence to approaches not its own.

The deadliness of breast cancer pushes women to organize and speak out about the disease. Inspired by the AIDS movement, organizations such as Breast Cancer Action Montreal seek to provide women with real choices. From opposing the tamoxifen trials to demanding that researchers investigate environmental causes of cancer, women are insisting that they have a role in the decisions that affect their lives. Sharon Batt writes, "From the moment of diagnosis, we are protagonists in a drama which may end in our death. If ever we should feel fully engaged, it is now."<sup>52</sup>

---

<sup>51</sup>Martindale, "My (Lesbian) Breast Cancer Story," 145.

<sup>52</sup>Batt, *Patient No More*, 287-88.



## **THE FUTURE OF HEALTH CARE: LESSONS FROM THE AIDS MOVEMENT**

**Alan Sears**

The 1990s are seeing health care systems scrutinized and rethought at many levels. In Windsor and Essex County, the District Health Council is directing a reconfiguration of health care which is couched in the highly optimistic terms of a "Win/Win Solution." However, the major dynamic driving this rethinking of health care delivery is actual or anticipated cutbacks in government funding.

The AIDS movement has important lessons to contribute to debates about the future of health care. The activist response to AIDS has produced a challenge to the established social relations in health care. The central focus of the AIDS movement has been to promote the control of people living with HIV/AIDS over their own bodies and lives. This has meant challenging the power of experts (such as doctors) and state officials to decide what is best for those affected by HIV/AIDS. This challenge has been accomplished through various forms of collective mobilization.

There is much of value to be learned from this challenge to the health care system. There is also, however, reason to fear that the wrong lessons will be learned in the present context. The AIDS movement was not about developing 'community-based' alternatives to the medical system. People living with HIV/AIDS need extremely expensive high-technology medical care as well as a variety of community-based services providing information, support, education, and advocacy. There is a great danger that policy-makers will use the rhetoric of the AIDS movement to put a progressive gloss on a straightforward reduction of services.

People living with AIDS in the early years of the epidemic faced blame, rejection, condemnation, inaction, and indifference at the highest levels of the health care system and the state. They organized, along with others affected by the epidemic, to struggle against that response. It would be the ultimate disservice to this mobilization to use it as a cynical justification for cutbacks to health care services. The real

lesson of the AIDS movement is not about the effectiveness of community-based services, but rather about the relationship between health and social justice.

*The AIDS Movement — Official Inaction*

The AIDS movement developed as an already politicized community mobilized to confront the epidemic in the face of official inaction. AIDS was first constructed as a syndrome in 1981 based on the reporting of clusters of cases of PCP and KS among gay men in New York and San Francisco. From the outset, AIDS was constructed as a 'gay disease.' Indeed, one of the early names given to the syndrome was GRID (Gay Related Immune Deficiency). In more popular terms it was known as 'gay cancer' or 'gay plague.'

The construction of AIDS as a 'gay disease' had an enormous impact on its development. The initial official response by governments in Canada, the United Kingdom and the United States was silence and inaction. The early years of the epidemic (approximately 1981-1985) saw virtually no government action in the areas of treatment, prevention or advocacy for people living with HIV/AIDS, not even in the limited form of official pronouncements that identified the problem. Many sources argue that this initial phase of inaction was connected to the construction of AIDS as a gay disease which would do no damage as long as it didn't bridge over into the 'general population.'<sup>1</sup>

The silence of this period was broken only for bouts of 'just say no' moralizing. AIDS was presented as the symptom of a moral problem, to be treated by campaigns which promoted rectitude through fear. Early British AIDS campaigns, for example, employed dire images of death to show the dangers of AIDS, yet offered no concrete advice on how to prevent infection except to avoid 'promiscuity.'<sup>2</sup> Gay men were told to avoid sex rather than how to have sex safely. This reflected an attitude that gay sex was something that could (and perhaps should) be avoided. It is difficult to imagine a similar injunction against heterosexual sex.

---

<sup>1</sup>Barry Adam, "The State, Public Policy and AIDS Discourse," *Contemporary Crises* 13 (1989): 1-14; Douglas Crimp, "How to Have Promiscuity in an Epidemic," in *AIDS: Cultural Analysis, Cultural Activism*, ed. Douglas Crimp (Cambridge: MIT Press, 1988), 237-71; and S Watney, "The Spectacle of AIDS," in *AIDS: Cultural Analysis*, ed. D Crimp (Cambridge: MIT Press, 1988), 71-86.

<sup>2</sup>Watney, "The Spectacle," 72-3.



Of course, AIDS is not the first medical condition to be approached in moral terms. Early in the twentieth century, tuberculosis was regarded as an indicator of 'moral degeneration' among the working classes in the urban centres of Britain, Canada, and the United States.<sup>3</sup> AM Brandt discussed the parallels between early AIDS campaigns and those mounted against sexually transmitted diseases at the time of World War I.<sup>4</sup> This moral dimension to public health campaigns has generally focused the blame for ill health onto those who suffer from it, shifting the spotlight away from the social conditions which promote ill-health (such as poverty) or the gaps in health care delivery.

The response to AIDS in terms of inaction combined with 'just say no' moralizing is very much connected to the construction of it as a 'gay disease'. From the earliest days, AIDS was associated with an 'epidemic of blame' which has impaired prevention and treatment endeavours.<sup>5</sup> Preventive efforts have been hampered by an unwillingness to speak frankly about gay sex (or sexuality in general) combined with a resilient belief among heterosexuals that a 'gay disease' could not infect them through straight sex. Treatment has been impeded by the persistence of AIDSphobia, the irrational fear of AIDS. The rational fear of AIDS, based on the use of effective measures to block the known routes of transmission, can help combat new infections. In contrast, the irrational fear of AIDS leads to various forms of 'quarantine' based on totally unfounded fears of casual contagion.

AIDSphobia has been remarkably resilient despite improved AIDS education. This resilience can be explained largely in terms of the correlation between AIDSphobia and homophobia, prejudicial attitudes against lesbians and gay men. Studies show that individuals with anti-gay attitudes are far more likely than others to have irrational fears about HIV transmission.<sup>6</sup>

---

<sup>3</sup>Frank Mort, *Dangerous Sexualities: Medico-Moral Politics in England since 1830* (London: Routledge, 1987), 203-09; Alan Sears, "'To Teach Them How To Live': The Politics of Public Health from Tuberculosis to AIDS," *Journal of Historical Sociology* 5, no. 1 (1992): 61-84; and Mariana Valverde, *The Age of Light, Soap and Water* (Toronto: McClelland and Stewart, 1991), 104-14.

<sup>4</sup>Allan M Brandt, *No Magic Bullet: A Social History of Venereal Disease in the United States*, rev. ed. (New York: Oxford University Press, 1987), 1-5.

<sup>5</sup>Renee Sabatier, *Blaming Others: Prejudice, Race and Worldwide AIDS* (London: Panos Institute, 1988), 2-64.

<sup>6</sup>J H Pleck, L O'Donnell, and C O'Donnell, "AIDSphobia, Contact With AIDS and AIDS-Related Job Stress in Hospital Workers," *Journal of Homosexuality* 15 (1988): 49.

The construction of AIDS as a gay diseases has been maintained despite many kinds of evidence to the contrary. Cases of AIDS were identified among people who were not gay in the very early days. Scientific knowledge of the routes of transmission for HIV clearly shows that unprotected heterosexual intercourse is a high risk for both partners. The vast majority of cases world wide (75 percent according to the World Health Organization) result from heterosexual transmission. It is still true in Canada that the gay male community has been the most affected by AIDS, but it is only through homophobia that this statistic is transformed into a myth of heterosexual immunity. Anti-gay attitudes underlie the deeply-held belief that 'normal' sex is somehow inherently safer.

### *Community Mobilization*

The construction of AIDS as a gay disease has had tragic consequences. The lives of people with HIV and AIDS are made far more difficult by the presence or anticipation of discrimination and irrational fears. Many people have been infected when that might have been prevented through effective intervention. Others carry on with unsafe activities with the false assurance that their 'normalcy' will save them.

At the same time, the development of AIDS in an already politicized community has led to important mobilizations in response to official inaction. These mobilizations, which I collectively label the 'AIDS movement', have ranged from informal networks through which people living with HIV/AIDS share knowledge about treatment to formal organizations which offer services (like the AIDS Committee of Windsor) or concentrate on political action (like AIDS Action NOW or ACT UP). The AIDS movement first developed in lesbian and gay communities, usually drawing on the skills and perspectives of people who had some experience in advocacy, community-building or political organizing.

The significance of the development of AIDS in an already politicized community goes beyond the presence of a skills base and an inventory of existing organizations. The AIDS movement built on the legacy of previous struggles for lesbian and gay rights. This legacy contributed to the development of an orientation to issues of health and illness, particularly around issues of the state, medical expertise, and the importance of collective action.

First, the AIDS movement developed with a somewhat oppositional approach to the state. The struggle against various forms of state



regulation has been a central feature of the lesbian/gay movement.<sup>7</sup> People who had fought against censorship and police harassment were unlikely simply to trust the goodwill of states that would not even recognize their rights or their relationships. Certainly, the AIDS movement has made demands on the state (for funding and services) but it has generally opposed measures that would increase state power over people living with HIV/AIDS (such as reporting by name the people who test HIV positive to public health authorities).

Secondly, the AIDS movement has been highly critical of 'experts' in general and medical practitioners in particular. Through much of the twentieth century homosexuality had been pathologized, treated as an illness. It was only in 1973 that the American Psychiatric Association removed homosexuality from the list of mental illnesses. People were unlikely to hand themselves over without reservations to a medical system that until quite recently had been trying to 'cure' them of being gay.

Thirdly, the lesbian/gay movement had taught people the importance of collective action. The contemporary lesbian/gay movement grew out of the Stonewall riots in June 1969. The gains that lesbians and gays have made since Stonewall can be attributed to the militancy and activism that have shaped the movement at its highest point. This experience in building a social movement provided a framework for responding to the AIDS crisis. AIDS could not be approached as an individual medical problem to be dealt with only through health care. Only a collective response could challenge the inaction and the prejudice that confronted people living with HIV and others affected.

### *Challenging Health Care*

The accomplishments of the AIDS movement have been crucial for people living with HIV/AIDS and others affected. The first accomplishment was the invention and popularization of safer sex education. The seminal 1983 pamphlet "How to Have Sex in an Epidemic" by Berkowitz, Callen and Dworkin is regarded as the first serious guide to the safer sex practices that are commonplace today.<sup>8</sup> These practices

---

<sup>7</sup>Barry Adam, *The Rise of a Gay and Lesbian Movement* (Boston: Twayne, 1987), 58-60; and Gary W Kinsman, *The Regulation of Desire: Sexuality in Canada* (Montreal: Black Rose, 1987), 31-34.

<sup>8</sup>J Z Grover, "Visible Lesions: Images of the PWA in America," in *Fluid Exchanges: Artists and Critics in the AIDS Crisis*, ed. James L Miller (Toronto: University of Toronto Press, 1992), 36.

did not originate with public health officials, who in the early period had focused basically on anti-sex and anti-promiscuity messages. The safer sex message was carried into the community by AIDS organizations who developed innovative, appropriate, and erotic ways of disseminating it in a variety of situations. The result was one of the most successful behavioural change campaigns in public health history. The use of safer sex among members of the gay male community is impressively high, even if there is still important work to be done in certain areas.

The second important accomplishment of the AIDS movement was the development of a network of support and advocacy services for people living with HIV/AIDS. AIDS service organizations across North America formed support groups and offered other services such as case management. Buddy systems linked people living with HIV on a one-on-one basis with trained volunteers who could help in a number of ways ranging from daily chores to personal discussion. AIDS service organizations acted as advocates for people living with HIV/AIDS in their dealings with the health care system, government services and other institutions. This has contributed to breaking down the isolation of people living with AIDS, provided a single point of entry to the wide variety of health and social services that may be required and challenged discrimination in treatment and service provision.

The third area of accomplishment for the AIDS movement has been in the dissemination of treatment information. AIDS-related medical conditions are particularly complex as they consist of a whole range of opportunistic infections developed in response to immune deficiency. It is a tremendous challenge for anyone to keep on top of this very wide range of medical problems as well as ongoing treatment developments. People living with HIV/AIDS often learned more from informal folk networks of peers than from their doctors. These networks have been formalized and it has become a major priority for AIDS services to get useful and accessible information into the hands of people living with HIV/AIDS.<sup>9</sup>

A fourth accomplishment of the AIDS movement has been winning demands for improved funding and services. Following the period of official inaction, the late 1980s and early 1990s saw a tremendous increase in funding to AIDS services as well as the release of

---

<sup>9</sup>See, for example, the impressive self-help publication, M Whitehead, and B Patterson, *Managing Your Health: A Guide for People Living with HIV or AIDS* (Toronto: Community AIDS Treatment Information Exchange and The Toronto People Living With AIDS Foundation, 1993).



experimental treatments and other important changes. The AIDS movement succeeded in placing considerable pressure on governments, drug companies and other organizations. These improved levels of service are certainly at risk as the wave of cutbacks sweeps through health, education, and social services in Canada, the United States and elsewhere.

Finally, the AIDS movement has succeeded in developing new ways of grieving appropriate to the memories of people who have died from AIDS-related causes and to those they leave behind. This has included the development of innovative forms of memorial service for individuals as well as public projects such as the AIDS quilts in the United States and Canada and the AIDS memorial in Cawthra Park in Toronto. At their best, these memorials have combined specific recognition of individuals who have died with a general sense of community loss, particularly in lesbian and gay communities where the losses have been devastating. They are often secular in tone, reflecting the diversity of the communities who have most directly felt the losses and the exclusion that members of these communities have felt from traditional religious institutions.

These accomplishments add up to a challenge to the social relations which shape health care in contemporary society. The AIDS movement has used collective action to increase the power of those whose health is at stake over their own bodies and lives. This has meant making the resources and information available to people affected so that they can make choices about treatment and prevention. The emphasis on the active role of those whose health is at stake is demonstrated even in the terminological preference for the label 'people living with HIV/AIDS' rather than 'AIDS victims' (implying passivity) or 'AIDS patients' (describing only a specific location in medical relations).<sup>10</sup>

The debate about HIV testing in the late 1980s and early 1990s provides an important example of the challenge mounted by the AIDS movement.<sup>11</sup> At that time, AIDS organizations generally supported anonymous testing which would permit people to find out their HIV status without providing identifying information that could be reported to public health officials. The test was exclusively for the use of the people being tested, permitting them to control completely information concerning the results. The AIDS movement argued that anonymous

---

<sup>10</sup>Crimp, "Promiscuity in an Epidemic," 239-40.

<sup>11</sup>An extended analysis of the politics of HIV testing can be found in Alan Sears "AIDS and the Health of Nations: The Contradictions of Public Health," *Critical Sociology* 18, no. 2 (1991): 31-50.

testing would provide the conditions under which more people would come forward to get tested as the first step in a process of taking control over their health.

Public health officials often opposed anonymous testing. They tended to support procedures compatible with the reporting of HIV-positive cases. They wanted to know who was infected to permit the tracing of previous sexual contacts and to monitor safer sex practices. AIDS activists fought against the use of these traditional public health practices on the grounds that they compromised the privacy and safety of people living with HIV/AIDS. They were concerned that these procedures might drive people underground, creating a situation where it was preferable to forego testing in order to avoid the intrusion of public health officials. In Ontario, the AIDS movement won on this issue and anonymous testing is now available at numerous locations across the province, including sites in Windsor.

None of this would have been possible without the support and participation of committed individuals within the health care system. The AIDS movement has, to a large extent, approached the health care system as an outsider, but it has relied the work of insiders in many areas. In cities across North America particular doctors and nurses invested tremendous time and good will in the up front learning required to assist with the medically highly complex treatment of people living with HIV. The AIDS movement has not necessarily been anti-medical, though it has certainly been highly critical of the health care system and the medical establishment.<sup>12</sup>

The AIDS movement did more than fill the vacuum left by official inaction. It developed an approach to health care that challenged established social relations in medicine. The movement's origins in the lesbian/gay community contributed in crucial ways to this approach. Yet this has also raised issues as the face of AIDS changes. It could be argued that a coalition model has been followed (with more or less success) in work with other politicized communities (women, ethno-cultural communities). This has certainly created stresses and strains and battles about priorities, though it has also produced some very useful programs that have taken the AIDS movement's approach in appropriately adapted forms to new communities.<sup>13</sup> The issue of how

---

<sup>12</sup>There is a current within the AIDS movement which is avidly anti-science and therefore anti-medical. The debates about the relationship of the AIDS movement to science and medicine lie outside the parameters of this paper.

<sup>13</sup>There has been a specific debate around the 'de-gaying' of AIDS: E Rofes, "Gay Groups vs. AIDS Groups: Averting Civil War in the 1990s," *Outlook* 2, no.



this model relates to communities who are not organized and politicized (e.g. injection drug users) or those outside the parameters of organized communities (e.g. men who have sex with men but do not identify as gay) remains an important one which has not been fully addressed.

### *Health Care and Control*

The AIDS movement is not the first to mount such a challenge to the relations of health care. There are notable parallels with the women's health movement and the struggle for workers' health and safety.<sup>14</sup> In each of these cases, health issues emerged in an already politicized context with pre-existing forms of organization. The women's liberation movement of the 1960s produced the women's health movement, while health and safety struggles have been connected to workplace organization, particularly unionization.

The struggle for information played an important role in these movements. The women's health movement saw the publication of important sources such as the book, *Our Bodies, Ourselves*, which aimed to educate women so that they could take charge of their own health.<sup>15</sup> The 'right to know' has played an important part in health and safety struggles, where workers demand accurate information about the risks associated with dangerous materials or situations. As well, each of these movements has gone beyond the right to know to demand the power to act. Unions have fought for the right to refuse unsafe work. Women's organizations have fought to develop the basic services (abortion clinics, women's health centres) required to offer women genuine choices.

Each of these movements has developed some embryonic form of the politics of health 'from below.' The central feature of this set of politics is an emphasis on people taking control over their bodies and lives through collective action. It is a challenge to the idea that health comes 'from above,' through the actions of the state or the medical system. Certainly, the struggle for health 'from below' necessarily includes demands for full access to comprehensive health care services.

---

4 (1990): 8-17. Critics such as Rofes argue that the AIDS organizations have been ditching their lesbian/gay identities in order to 'pass' as health agencies. These critics see a broader focus for the AIDS movement, not as a step in the direction of inclusiveness but rather as a capitulation to homophobia.

<sup>14</sup>These parallels are explored in detail in Sears, "Contradictions," 41-42.

<sup>15</sup>Boston Women's Health Collective, *The New Our Bodies, Ourselves* (New York: Simon and Schuster, 1984), 3-4.

It also includes demands about the way these services are organized, challenging the power relations implicit in the medical model, such as the control exercised by experts. It goes demanding a role for 'consumers,' a very popular term in health care planning drawn from the market place which describes the place of individuals in the purchase of commodities. The model of shopping does not place sufficient emphasis on the idea of people whose health is at stake as activists on their own behalf.

It is important, in the current context, to distinguish health-care-from-below from health-care-on-the-cheap. The critique of the social relations of health care can be appropriated to serve as window-dressing for cutbacks. That is certainly what happened through the program of psychiatric de-institutionalization in the 1970s and 1980s.<sup>16</sup> Governments took up the language of community-based alternatives as they shut down repressive psychiatric institutions. They did not seriously engage in the development of alternatives and in the end people wanting or needing help for mental health problems were left with fewer available services. Paul Martin's 1995 budget makes it very clear that we are facing a context of cutbacks in which it is logical to suspect that any shift in the organization of health care delivery is simply a way of packaging service reductions and lay-offs.

People living with HIV and AIDS have benefitted from top quality hospital care as well as community services. No number of buddies, support groups, or case managers can replace good hospital treatment and care for those who need it. The aim has been to improve access to medical services, not to erode them. No amount of treatment information can replace the diagnostic and therapeutic skills of medical professionals. The aim has been to challenge the experts' monopoly on knowledge, not the existence of experts.

The final lesson from the AIDS movement concerns the limits of health care. It is possible to challenge and improve health care, to make demands for full access to comprehensive health care under the control of those whose bodies and lives are at stake. It is possible to win some victories that lead to genuine reforms. However, these reforms can only go so far in a society based on inequality.

For people to be truly healthy, we need a healthy society. On a global scale, poverty is the sharpest indicator of risk for HIV infection

---

<sup>16</sup>John Marshall, *Madness: An Indictment of the Mental Health Care System in Ontario* (Toronto: Ontario Public Service Employees Union, 1982), 45-59; and Andrew T Scull, *Decarceration: Community Treatment and the Deviant* (Englewood Cliffs, NJ: Prentice-Hall, 1977), 180-84.



(the poorer someone is, the more likely he/she is to be infected).<sup>17</sup> The 1990s are seeing an intensification rather than reduction of poverty on a global scale. People living with HIV/AIDS will suffer from deep cuts in health care and social programs as well as the erosion of international assistance and chronically high unemployment. The return of public health threats such as cholera and tuberculosis is a sign of a world where absolute poverty is on the increase.

Poverty is not the only manifestation of inequality that is related to ill-health. Discrimination against lesbians and gays has contributed in many ways to the spread of HIV infection, whether through official inaction or the false reassurance among heterosexuals that they could not catch a 'gay disease.' Sexism contributes to ill-health, for example making it very difficult for women to insist on safer sex practices. Racism contributes to the chronic neglect of the health needs of people of colour and aboriginal peoples.

The control over our bodies and lives cannot be achieved through good health care alone. It requires an exhaustive challenge to social relations of inequality at every level of society. The AIDS movement has offered a number of important lessons about what health is and how to obtain it. It has produced important developments in services and programs. It has shown the importance of collective action in the struggle for health. The ultimate lesson of the AIDS movement, however, is that the struggle for health is at the same time a struggle for social justice, against all forms of inequality and discrimination.

---

<sup>17</sup>Sabatier, *Blaming Other*, 4.

## CONTRIBUTORS

**Mary Louie Drake** is an associate professor in the School of Nursing at the University of Windsor. Her interests are obstetrics and community health. She completed midwifery studies in England. As well, she has worked in Africa and in the Middle East.

**Anne Forrest's** research is at the intersection of industrial relations and women's issues. She has presented papers at the annual meeting of the Canadian Industrial Relations Association. These papers gave a feminist perspective on such themes as unions and women, sexual harassment in the workplace, and collective bargaining. Her feminist interpretations of industrial law and the politics of the union movement have led to grants from the University of Windsor and SSHRCC and to publication of a number of articles and chapters in books.

**Maureen Muldoon**, an ethicist with an interest in a wide range of health care issues, is associate professor in the Department of Religious Studies at the University of Windsor and a bioethics consultant for Hotel-Dieu Grace Hospital in Windsor. She has published a sourcebook and an annotated bibliography on the abortion debate. Currently she is pursuing research on clergy ethics in the Anglican and United Churches in Ontario and Saskatchewan.

**Alan Sears'** research focuses on a range of topics including sociological theory and the social aspects of HIV/AIDS. With Barry Adam and Glen Schellenberg, he has been awarded a grant from the National Health Research and Development Programme to continue research on "AIDS and Safer Sex Strategies." Recent articles have appeared in *Medical Anthropology*, *The Canadian Review of Sociology and Anthropology* and the *Windsor Review of Law and Social Issues*. Dr Sears is an associate professor in the Department of Sociology and Anthropology at the University of Windsor.



## PARTICIPANTS

Lynne Amort	Centres for Seniors and Ontario Breast Screening Programme
Frank Bagatto	Hotel-Dieu Grace Hospital
Patti Bezaire	Heart and Stroke Foundation
Barb Billey	Wellness Coalition
Isabelle Cimolino	Sandwich Community Health Centre
Elizabeth Collins	Huron Lodge (Home for Seniors)
Shirley Gottlieb	Victorian Order of Nurses
Patrick Holland	Roman Catholic Children's Aid Society
Martha Horsburgh	Registered Nurses Association of Ontario
W K Jaggs	Teen Health Centre
Bill Karr	Worker's Compensation Board
Steve Lough	District Health Council
Mary Kaye Lucier	Bulimia Anorexia Nervosa Association
Lucy Marcus	Huron Lodge (Home for Seniors)
Christine May	Hospice of Windsor
Badmini Raju	Windsor Women Working with Immigrant Women
Bill Reeves	Community Mental Health Clinic
Karen Rockwell-Georgiou	House of Sophrosyne
Pat St. Louis	Wellness Coalition
Ken Schneider	Windsor Regional Cancer Centre
Rita Sobocan	Reach for Recovery % Canadian Cancer Society
Marilyn Sutton	HIV Care Programme
Kenn Stanton	AIDS Committee of Windsor
Joy Veres	Chaplain with Seniors

## SUGGESTED FURTHER READINGS

### BOOKS

- ACT-UP/New York Women and AIDS Book Group. *Women, AIDS and Activism*. Boston: South End Press, 1990.
- Aggleton, P, P Davies, and G Hart. *AIDS: Individual, Cultural and Policy Dimensions*. Lewes, East Sussex: Falmer Press, 1990.
- Aggleton, Peter et al., eds. *AIDS: Social Representations, Social Practices*. Lewes, East Sussex: Falmer Press, 1989.
- Aggleton, Peter, and Hilary Homans, eds. *Social Aspects of AIDS*. London: Falmer Press, 1988.
- Allentuck, Richard. *Who Speaks for the Patient? The Crisis in Canadian Health Care*. Toronto: Burns and MacEachren, 1978.
- Altman, Dennis. *AIDS in the Mind of America: The Social, Political and Psychological Impact of a New Epidemic*. New York: Doubleday, 1986
- American Cancer Society. *Summary of Current Guidelines for the Cancer-Related Check-up: Recommendations*. Atlanta: American Cancer Society, 1988.
- Arras, John, and Nancy K Rhoden. *Ethical Issues in Modern Medicine*. Mountain View, CA: Mayfield Publishing, 1989.
- Barasch, Marc Ian. *The Healing Path: A Soul Approach to Illness*. New York: Tarcher/Putnam Books, 1993.
- Bateson, Mary Catherine, and Richard Goldsby. *Thinking AIDS*. Reading, MA: Addison-Wesley, 1988.
- Batt, Sharon. *Patient No More: The Politics of Breast Cancer*. Charlottetown, PEI: Gynery Books, 1994.
- Bayer, Ronald. *Private Acts, Social Consequences: AIDS and the Politics of Public Health*. New York: The Free Press, 1989.



## 42 Suggested Further Readings

- Baylis, Françoise. *The Health Care Ethics Consultant*. Totowa, NJ: Humana Press, 1994.
- Baylis, Françoise, and Jocelyn Grant Downie. *Codes of Ethics: Ethics Codes, Standards and Guidelines for Professionals Working in a Health Care Setting in Canada*. Toronto: Department for Bioethics, Hospital for Sick Children, 1992.
- Beauchamp, Tom L, and LeRoy Walters. *Contemporary Issues in Bioethics*. 4th ed. Belmont, CA: Wadsworth, 1994.
- Bell, Nora K. *Who Decides? Conflicts of Rights in Health Care*. Clifton, NJ: Humana Press, 1982.
- Bepko, C, ed. *Feminism and Addiction*. New York: The Haworth Press, Inc., 1991.
- Blanchet, Kevin D, ed. *AIDS: A Health Care Management Response*. Rockville, MD: Aspen Publishers, 1988.
- Boffin, Tessa, and Sunil Gupta, eds. *Ecstatic Antibodies: Resisting the AIDS Mythology*. London: Rivers Oram Press, 1990.
- Bolaria, B Singh, and Rosemary Bolaria. *Women, Medicine and Health*. Halifax, NS: Fernwood, 1994.
- Borysenko, Joan. *Minding the Body, Mending the Mind*. New York: Bantam Books, 1988.
- Bovey, S. *Being Fat is Not a Sin*. London: The Women's Press. 1989.
- Bregman, Lucy, and Sara Thiermann. *First Person Mortal*. New York: Paragon, 1995.
- Brody, Eugene B. *Biomedical Technology and Human Rights*. Alexandria, VA: WFMH, 1993.
- Brody, Howard. *Stories of Sickness*. New Haven: Yale University Press, 1987.
- Broyard, Anatole. *Intoxicated By My Illness*. New York: Clarkson Potter, 1992.
- Bulger, RuthEllen, Elizabeth Heitman, and Stanley Joel Reiser. *The Ethical Dimensions of the Biological Sciences*. Cambridge, NY: Cambridge University Press, 1993.
- Butler, Sandra, and Barbara Rosenblum. *Cancer in Two Voices*. San Francisco: Spinsters Book Company, 1991.
- Callahan, J, ed. *Menopause. A Midlife Passage*. Bloomington and Indianapolis: Indiana University Press, 1993.
- Camenisch, Paul F. *Religious Methods and Resources in Bioethics*. Dordrecht, Netherlands and Boston: Kluwer Academic Publishers, 1994.

- Canadian AIDS Society. *Homophobia, Heterosexism and AIDS: Creating a More Effective Response to AIDS*. Ottawa: Canadian AIDS Society, 1991.
- Cantor, Norman L. *Advance Directives and the Pursuit of Death with Dignity*. Bloomington: Indiana University Press, 1993.
- Caplan, Arthur L. *If I Were a Rich Man Could I Buy a Pancreas? And Other Essays on the Ethics of Health Care*. Bloomington: Indiana University Press, 1992.
- Carter, Erica, and Simon Watney, eds. *Taking Liberties: AIDS and Cultural Politics*. London: Serpent's Tail, 1989.
- Carver, Cynthia. *Patient Beware: Dealing With Doctors and Other Medical Dilemmas*. Scarborough, ON: Prentice-Hall Canada Inc., 1984.
- Cassels, Eric. *The Nature of Suffering and the Goals of Medicine*. New York: Oxford University Press, 1991.
- Charman, Robert C. *At Risk: Can the Doctor-Patient Relationship Survive in a High-Tech World?* Dublin, NH: W L Bauhan, 1992.
- Cooper, W. *No Change: A Biological Revolution for Women*. 2d rev. ed. London: Arrow, 1983.
- Corless, Inge B, and Mary Pittman-Lindeman, eds. *AIDS: Principles, Practices, and Politics*. New York: Hemisphere, 1988.
- Cousins, Norman. *Anatomy of an Illness As Perceived By the Patient*. 2d ed. New York: Bantam, 1981.
- Crimp, Douglas, ed. *AIDS: Cultural Analysis/Cultural Activism*. Cambridge: MIT Press, 1988.
- \_\_\_\_\_. *AIDS Demographics*. Seattle: Bay Press, 1990.
- Dackman, Linda. *Affirmations, Meditations and Encouragements for Women Living with Breast Cancer*. New York: Harper Collins, 1993.
- Day, N E, and A B Miller. *Screening for Breast Cancer*. Toronto: Hans Huber, 1988.
- Dixon, John. *Catastrophic Rights: Experimental Drugs and AIDS*. Vancouver: New Star, 1990.
- Dodd, Dianne E, and Deborah Gorham. *Caring and Curing: Historical Perspectives on Women and Healing in Canada*. Ottawa: University of Ottawa Press, 1994.
- Doyal, Lesley. *What Makes Women Sick? Gender and the Political Economy of Health*. London: Macmillan, 1995.
- Dreifus, C, ed. *Seizing our Bodies: The Politics of Women's Health*. New York: Vintage Books, 1977.



#### 44 Suggested Further Readings

- Duh, Samuel V. *Blacks and AIDS: Causes and Origins*. Newbury Park, CA: Sage, 1991.
- Dunstan, Gordon Reginald, and Elliot A Shinebourne. *Doctor's Decisions: Ethical Conflicts in Medical Practice*. Oxford and New York: Oxford University Press, 1989.
- Ehrenreich, B, and D English. *For Her Own Good: 150 Years of Experts' Advice to Women*. Garden City, NY: Anchor Books, 1979.
- Englehardt, H Tristan. *Bioethics and Secular Humanism: The Search for a Common Morality*. London: SCM Press; Philadelphia: Trinity Press International, 1991.
- \_\_\_\_\_. *The Foundations of Bioethics*. New York: Oxford University Press, 1986.
- Estaugh, V, and J Wheatley. *Family Planning and Family Well-Being*. London: Family Policy Studies Centre, 1990.
- Fee, Elizabeth, and Daniel M Fox, eds. *AIDS: The Burdens of History*. Berkeley: University of California Press, 1988.
- Fettner, Ann Giudici, and William Check. *The Truth About AIDS: The Evolution of an Epidemic*. New York: Holt, 1985.
- Friedman, Emily. *Choices and Conflict Explorations in Health Care Ethics*. Chicago: American Hospital Publishers, 1992.
- Frankenhaueser, M, U Lundberg, and M Chesney, eds. *Women, Work and Health: Stress and Opportunities*. New York: Plenum Press, 1991.
- Garrett, Thomas M, Harold W Baillie, and Rosellen M Garrett. *Health Care Ethics: Principles and Problems*. Englewood Cliffs, NJ: Prentice Hall, 1989.
- Ginzberg, Eli, Miriam Ostow, and Anna B Dutka. *The Economics of Medical Education*. New York: Josiah Macy Jr Foundation, 1993.
- Golub, S. *Periods. From Menarche to Menopause*. Newbury Park: Sage, 1992.
- Graubard, Stephen R, ed. *Living With AIDS*. Cambridge: MIT Press, 1990.
- Greaves, M. *Big and Beautiful: Challenging the Myths and Celebrating Our Size*. London: Grafton, 1990.
- Gunderson, Martin, David J Mayo, and Frank S Rhame. *AIDS: Testing and Privacy*. Salt Lake City: University of Utah Press, 1989.
- Hauerwas, Stanley. *Naming the Silences: God, Medicine and the Problem of Suffering*. Grand Rapids, MI: Eerdmans Publishing Company, 1990.
- Herdt, Gilbert, and Shirley Lindenbaum, eds. *The Time of AIDS: Social Analysis, Theory, and Method*. Newbury Park, CA: Sage, 1992.

- Holmes, Helen B, Betty B Hoskins, and Michael Gross. *Custom-Made Child? Women-Centred Perspectives*. Clifton, NJ: Humana Press, 1981.
- Holmes, Helen B, and Laura Martha Purdy. *Feminist Perspectives in Medical Ethics*. Bloomington: Indiana University Press, 1992.
- Huber, Joan, and Beth E Schneider, eds. *The Social Context of AIDS*. Newbury Park, CA: Sage, 1992.
- Humber, James M, and Robert F Almeder. *Biomedical Ethics Reviews*. Clifton, NJ: Humana Press, 1982.
- Jäger, Hans, J Welch, and J L Francis. *AIDS Phobia: Disease Pattern and Possibilities of Treatment*. Chichester, England and East Horwood, NY: Halsted Press, 1988.
- Jones, M. *Secret Flowers: Mourning and the Adaptation to Loss*. London, The Women's Press, 1988.
- Kaye, Dennis. *Laugh, I Thought I'd Die: My Life with ALS*. Toronto: Viking Penguin Books, 1993.
- Kaye, Ronnie. *Spinning Straw into Gold*. New York: Simon and Shuster, 1991.
- King, Alan J C. *Canada Youth and AIDS*. Kingston, ON: Queen's University, 1989.
- \_\_\_\_\_. *Street Youth and AIDS*. Kingston, ON: Queen's University, 1990.
- Kleinman, Arthur. *The Illness Narratives*. New York: Basic Books, 1988.
- Kramer, Larry. *Reports from the Holocaust: The Story of an AIDS Activist*. New York: St. Martin's, 1994.
- Kübler-Ross, Elisabeth. *AIDS: The Ultimate Challenge*. New York: Macmillan; London: Collier Macmillan, 1987.
- \_\_\_\_\_. *On Death and Dying*. New York: Macmillan, 1969.
- Kushner, Harold S. *When Bad Things Happen to Good People*. New York: Schocken Books, 1981.
- Levin, Beatrice. *Women and Medicine*. 2d ed. Lincoln, NE: Media Publishers, 1988.
- Levine, Stephen. *Meetings at the Edge: Conversations with the Grieving and the Dying, the Healing and the Healed*. New York: Doubleday, 1984.
- \_\_\_\_\_. *Who Dies: An Investigation of Conscious Living and Dying*. New York: Doubleday, 1982.
- Locke, Steven, and Douglas Colligan. *The Healer Within: The New Medicine of Mind and Body*. New York: E P Dutton, 1986.



#### 46 Suggested Further Readings

- Lockwood, Michael. *Moral Dilemmas in Modern Medicine*. London and New York: Oxford University Press, 1985.
- Lorde, Audre. *The Cancer Journal*, 2d ed. San Francisco: Spinsters/Aunt Lute, 1980.
- Love, Susan, and Karen Lindsey. *Dr Susan Love's Breast Book*. Reading, MA: Addison-Wesley Publishing, 1991.
- Maestri, William. *Basic Ethics for the Health Care Professional*. Washington, DC: University Press of America, 1982.
- Mappes, Thomas A, and Jane S Zembaty. *Biomedical Ethics*. Maidenhead, Berks, UK and New York: McGraw-Hill, 1991.
- May, William. *The Patient's Ordeal*. Bloomington: Indiana University Press, 1991.
- Mayer, Musa. *Examining Myself: One Woman's Story of Breast Cancer Treatment and Recovery*. Winchester, MA: Faber and Faber, 1993.
- McCarthy, Donald G, and Edward J Bayer. *Handbook on Critical Life Issues*. Braintree, MA: Pope John Centre, 1988.
- McKeown, Thomas. *The Role of Medicine: Dream, Mirage or Nemesis?* Princeton: Princeton University Press, 1979.
- McPhie, Rosalind. *Picasso's Woman*. Toronto: Douglas and McIntyre, 1994.
- Miller, David. *Living with AIDS and HIV*. London: Macmillan, 1987.
- More, Ellen Singer, and Maureen A Milligan. *The Empathic Practitioner: Empathy, Gender and Medicine*. New Brunswick, NJ: Rutgers University Press, 1994.
- Nessin, Susan, and Joyce Ellis. *Cancervive*. Boston: Houghton Mifflin, 1991.
- Nicholson, P, and J Ussher, eds. *The Psychology of Women's Health and Health Care*. Basingstoke: Macmillan, 1992.
- Northrup, Christiane. *Women's Bodies, Women's Wisdom: Creating Physical and Emotional Health and Healing*. New York: Bantam Books, 1994.
- O'Grady, Lois F. *A Practical Approach to Breast Disease*. Boston: Little, Brown, and Co., 1995.
- O'Malley, Martin. *Hospital: Life and Death in a Major Medical Centre*. Toronto: Macmillan of Canada, 1986.
- O'Neil, Edward H. *Health Professions Education for the Future: Schools in Service to the Nation*. San Francisco: Pew Health Professions Commission, 1993.

- Olivotto, Ivo, Karen Gelmon, and Urve Kuusk. *Breast Cancer: All You Need to Know to Take an Active Part in Your Treatment*. Vancouver: Intelligent Patient Guide Ltd., 1995.
- Patton, Cindy. *Last Served: Gendering the AIDS Pandemic*. London: Taylor and Francis, 1994.
- \_\_\_\_\_. *Inventing AIDS*. New York: Routledge, 1990.
- \_\_\_\_\_. *Sex and Germs: The Politics of AIDS*. Montreal: Black Rose Books, 1986.
- Pellegrino, Edmund D, and David C Thomasma. *For the Patient's Good: The Restoration of Beneficence in Health Care*. New York: Oxford University Press, 1988.
- Pfeiffer, Catherine H, and John B Mulliken. *Caring for the Patient with Breast Cancer: An Interdisciplinary/Multi-disciplinary Approach*. Reston, VA: Reston Publishing, 1984.
- Pfeiffer, N. *The Stork and the Syringe: A Political History of Reproductive Medicine*. London: Polity, 1993.
- Preston, Thomas. *The Clay Pedestal: A Re-examination of the Doctor-Patient Relationship*. Seattle: Madrona Books, 1981.
- Price, J. *Motherhood: What It Does To Your Mind*. London: Pandora, 1988.
- Price, Monroe E. *Shattered Mirrors: Our Search for Identity and Community in the AIDS Era*. Cambridge: Harvard University Press, 1989.
- Purtilo, Ruth B. *Ethical Dimensions in the Health Professions*. 2d ed. Philadelphia: W B Saunders Co., 1993.
- Rachlis, Michael, and Carol Kushner. *Strong Medicine: How to Save Canada's Health Care System*. Toronto: HarperCollins, 1994.
- \_\_\_\_\_. *Second Opinion: What's Wrong With Canada's Health Care System and How to Fix It*. Toronto: HarperCollins, 1989.
- Ray, Colette. *Psychological Aspects of Early Breast Cancer*. New York: Springer-Verlag, 1985.
- Richardson, C R. *Mind Over Cancer*. London: W. Foulsham and Company, Ltd., 1988.
- Richardson, Diane. *Women and the AIDS Crisis*. London: Pandora Press, 1989.
- Ring, Kenneth. *Heading Toward Omega: In Search of the Meaning of the Near-Death Experience*. New York: William Morrow & Co., 1984.
- Robison, Wade L, and Michael S Pritchard. *Medical Responsibility: Paternalism, Informed Consent, and Euthanasia*. Clifton, NJ: Humana Press, 1979.



## 48 Suggested Further Readings

- Rodwin, Marc A. *Medicine, Money and Morals: Physicians' Conflicts of Interest*. New York: Oxford University Press, 1993.
- Roy, David J. *Bioethics in Canada*. Scarborough, ON: Prentice-Hall Canada, 1994.
- Ruskin, Cindy, and Matt Heron. *The Quilt: Stories from the Names Project*. New York: Pocket Books, 1988.
- Schneider, Beth E, and Nancy E Stoller. *Women Resisting AIDS*. Philadelphia: Temple, 1995.
- Sears, J T, ed. *Sexuality and the curriculum: The Politics and Practices of Sexuality Education*. Columbia University: Teachers College Press, 1992.
- Seligman, Martin E P. *Helplessness: On Depression, Development and Death*. New York: W H Freeman, 1975.
- Seligson, M Ross, and Karen E Peterson. *AIDS Prevention and Treatment: Hope, Humour, and Healing*. New York: Hemisphere Publishing Corporation, 1992.
- Sherwin, Susan. *No Longer Patient: Feminist Ethics and Health Care*. Philadelphia: Temple University Press, 1992.
- Shilts, Randy. *And the Band Played On: Politics, People, and the AIDS Epidemic*. New York: St Martin's Press, 1987.
- Siegel, Bernie S. *Love, Medicine and Miracles: Lessons Learned About Self-Healing from a Surgeon's Experience with Exceptional Patients*. New York: Harper & Row, 1986.
- \_\_\_\_\_. *Peace, Love and Healing: Bodymind Communication and the Path of Self-Healing*. New York and Toronto: Perennial Library, 1990.
- Smith, George, and Eric Mykhalovskiy. *Hooking Up to Social Services*. Toronto: Community AIDS Treatment Information Exchange, 1995.
- Smith, John M. *Women and Doctors: A Physician's Explosive Account of Women's Medical Treatment — and Mistreatment — in America Today and What You Can Do About It*. New York: Atlantic Monthly Press, 1992.
- Smith, P. *The Emotional Labour of Nursing: How Nurses Care*. London: Macmillan, 1992.
- Sontag, S. *Illness as Metaphor and AIDS and its Metaphors*. London: Penguin, 1991.
- \_\_\_\_\_. *Illness as Metaphor*. New York: Vintage, 1989.
- Spiegel, David. *Living Beyond Limits: New Hope and Help for Facing Life-Threatening Cancer*. New York: Times Books, 1993.

- Spallone, P. *Generation Games: Genetic Engineering and the Future of Our Lives*. London: The Women's Press; Philadelphia: Temple University Press, 1992.
- Spurgeon, David. *Understanding AIDS: A Canadian Strategy*. Toronto: Key Porter Books, 1988.
- Tatchell, Peter. *AIDS: A Guide to Survival*. 3d ed. London: GMP Publishers, 1990.
- Thomas, John E. *Well and Good: Case Studies in Biomedical Ethics*. Peterborough, ON: Broadview Press, 1987.
- Toombs, S Kay, David Barnard, and Ronald Carson. *Chronic Illness: From Experience to Policy*. Bloomington and Indianapolis: Indiana University Press, 1995.
- Toombs, S Kay. *The Meaning of Illness: A Phenomenological Account of the Different Perspectives of the Physician and Patient*. Dordrecht, Netherlands: Kluwer Academic Publishing, 1993.
- VanDeVeer, Donald, and Tom Regan. *Health Care Ethics: An Introduction*. Philadelphia: Temple University Press, 1987.
- Veatch, Robert M. *Cross-Cultural Perspectives in Medical Ethics: Readings*. Boston: Jones and Bartlett, 1989.
- Vines, G. *Raging Hormones. Do They Rule our Lives?* London: Virago, 1993.
- Wachter, Robert M. *The Fragile Coalition: Scientists, Activists, and AIDS*. New York: St Martin's Press, 1991.
- Wadler, Joyce. *My Breast*. New York: Pocket Books, 1992.
- Watney, Simon. *Policing Desire: Pornography, AIDS and the Media*. London: Methuen, 1987.
- Weil, Andrew. *Health and Healing: Understanding Conventional and Alternative Medicine*. Boston: Houghton Mifflin, 1983.
- Wertz, Richard W. *Readings on Ethical and Social Issues in Biomedicine*. Englewood Cliffs, NJ: Prentice-Hall, 1973.
- Williams, A Paul. *The Feminization of Canadian Medicine: Implications for Health Care Delivery*. North York, ON: Institute for Social Research, York University, 1990.
- Williams, John R. *Biomedical Ethics in Canada*. Lewiston, NY: E Mellen Press, 1986.
- Williams, Penelope. *That Other Place*. Toronto: Dundern, 1993.
- Wilson, Doug. *Labour of Love*. Toronto: McClelland and Stewart, 1994.



## 50 Suggested Further Readings

- Winslade, William J. *Choosing Life or Death: A Guide for Patients, Families, and Professionals*. New York: Free Press; London: Collier Macmillan, 1986.
- Youngner, Stuart J. *Human Values in Critical Care Medicine*. New York: Praeger, 1986.

### ARTICLES

- Alderson, Priscilla. "Abstract Bioethics Ignores Human Emotions." *Bulletin of Medical Ethics* 68 (May 1991): 13-21.
- Aoun, Hacib. "From the Eye of the Storm, With the Eyes of a Physician." *Annals of Internal Medicine* 116 (15 February 1991): 335-38.
- Barthelome, William G. "A Revolution in Understanding: How Ethics Has Transformed Health Care Decision Making." *Quality Review Bulletin* 18 (January 1992): 6-11.
- Barton, Marie, and Ghislain Devroede. "Face to Face: A Dialogue Between a Patient and a Surgeon — Lack of Communication Prolonged My Hospital Stay." *Humane Medicine* 7 (Winter 1991): 54-58.
- Blustein, Jeffrey. "Doing What the Patient Orders: Maintaining Integrity in the Doctor-Patient Relationship." *Bioethics* 7 (July 1993): 290-314.
- Boisaubin, Eugene V. "Ethical and Legal Issues in the Treatment of Patients with AIDS." *Texas Medicine* 87 (February 1991): 76-80.
- Brazier, Margaret, and Mary Lobjoit. "AIDS, Ethics and the Respiratory Physician." *Thorax* 45 (April 1990): 283-86.
- Brescia, Frank J. "Killing the Known Dying: Notes of a Death Watcher." *Journal of Pain and Symptom Management* 6 (July 1991): 337-39.
- Campion, Edward W. "Why Unconventional Medicine?" Editorial. *New England Journal of Medicine* 328 (28 January 1993): 282-83.
- Chez, Ronald A, and Franklin J Apfel. "Women's Health Care: Rights and Responsibilities." *Women's Health Issues* 2 (Fall 1992): 133-36.
- Clarke, J N. "Sexism, Feminism and Medicalism: A Decade Review of Literature on Gender and Illness." *Sociology of Health and Illness* 5, no. 1 (1983): 63-82.
- Coulehan, Jack. "I Treat All My Patients Aggressively." *Journal of Medical Humanities* 11 (Winter 1990): 193-97.
- Curzer, Howard J. "Is Care a Virtue for Health Care Professionals?" *Journal of Medicine and Philosophy* 18 (February 1993): 51-69.

*Suggested Further Readings 51*

- Degner, Lesley F, and Jeffrey A Sloan. "Decision Making During Serious Illness: What Role Do Patients Really Want to Play?" *Journal of Clinical Epidemiology* 45 (September 1992): 941-50.
- Donovan, Jenny L, and David R Blake. "Patient Non-Compliance: Deviance or Reasoned Decision-Making?" *Social Science and Medicine* 34 (March 1992): 507-13.
- Dozor, Robert B, and Ken S Meece. "Relationships with AIDS Patients: Clinical Metaphors and Preventive Bioethics." *Family Medicine* 22 (November/December 1990): 474-77.
- Dyck, Arthur J. "Being a Physician and Being Ethical." *Linacre Quarterly* 59 (August 1992): 82-90.
- England, Stephanie Legg, and Jeremy Evans. "Patients' Choices and Perceptions After an Invitation to Participate in Treatment Decisions." *Social Science and Medicine* 34 no. 11 (1992) 1217-25.
- Freedman, Amy. "The Physician-Patient Relationship and the Ethic of Care." *Canadian Medical Association Journal* 148 (March 1993): 1037-43.
- Gauthier, Candace C, and Eleanor Krassen-Maxwell. "Time Demands and Medical Ethics in Women's Health Care." *Health Care for Women International* 12 (April/June 1991): 153-65.
- Gillick, Muriel R. "From Confrontation to Cooperation in the Doctor-Patient Relationship." *Journal of General Internal Medicine* 7 (January/February 1992): 83-86.
- Gillon, Raanan. "Caring, Men and Women, Nurses and Doctors, and Health Care Ethics." Editorial. *Journal of Medical Ethics* 18 (December 1992): 171-72.
- Grundstein-Amado, Riuka. "Physician-Patient Relationship As an Educational Experience." *Humane Medicine* 7 (Winter 1991): 23-28.
- Haas, Jennifer S et al. "Discussions of Preferences for Life-Sustaining Care by Persons with AIDS: Predictors of Failure in Patient-Physician Communication." *Archives of Internal Medicine* 153 (24 May 1993): 1241-48.
- Harrison, Donald C. "Science for the 21st Century: The Coming Biomedical Revolution." In *Preparing for Science in the 21st Century*, eds. Donald C Harrison, Marian Osterweis, and Elaine R Rubin, 5. Washington DC: The Association of Academic Health Centres, 1991.
- Kasper, J F, A G Mulley, and J E Wennberg. "Developing Shared Decision-Making Programs to Improve the Quality of Health Care." *Quality Review Bulletin* 18 (1992): 183-90.
- Lebacqz, Karen. "Feminism and Bioethics: An Overview." *Second Opinion* 17 (October 1991): 11-25.



## 52 Suggested Further Readings

- Lomas, Jonathan, Geoffrey M Anderson, Karin Domnick-Pierre, Eugene Vayda, Murray W Enkin and Walter J Hannah. "Do Practice Guidelines Guide Practice? The Effect of a Con-sensus Statement on the Practice of Physicians." *New England Journal of Medicine* 321 (1989): 1306-11.
- Manuel, C et al. "AIDS: The Rights and Duties of Health-Care Providers." *AIDS and Public Policy Journal* 6 (Spring 1991): 37-40.
- Mappes, Thomas A, and Jane S Zembaty. "Patient Choices, Family Interests, and Physician Obligations." *Kennedy Institute of Ethics Journal* 4 (March 1994): 27-46.
- Martindale, Kathleen. "My (Lesbian) Breast Cancer Story: Can I Get a Witness?" In *Resist: Essays Against a Homophobic Culture*, eds. Mona Oikawa, Dionne Falconers and Ann Decter, 137-50. Toronto: Women's Press, 1994.
- Maticka-Tyndale, Eleanor. "Social Construction of HIV Transmission and Prevention Among Heterosexual Young Adults." *Social Problems* 39 (1992): 238-52.
- Meyer, Michael J. "Patients' Duties." *Journal of Medicine and Philosophy* 17 (October 1992): 541-55.
- Morgan, Robin et al. "The Politics of Breast Cancer." *Ms.* 3, no 6 (1993): 37-60. Special issue devoted to breast cancer issues.
- Pellegrino, Edmund D. "An Ethic of Trust in an Era of Distrust." *Humane Medicine* 8 (October 1992): 268-69.
- Petersdorf, Robert G, and Marjorie P Wilson. "The Four Horsemen of the Apocalypse: Study of Academic Medical Centre Governance." *Journal of American Medical Association* 247, no. 8 (26 February 1982): 1154-55.
- Redelmeier, Donald A, Paul Rozin and Daniel Kahneman. "Understanding Patients' Decisions: Cognitive and Emotional Perspectives." *Journal of the American Medical Association* 270 (7 July 1993): 72-76.
- Reiser, Stanley Joel. "The Era of the Patient: Using the Experience of Illness in Shaping the Missions of Health Care." *Journal of the American Medical Association* 269 (24 February 1993): 1012-17.
- Richardson, William C. "Health Insurance in the USA." In *The Oxford Companion to Medicine*, John Walton, Paul B Beeson, and Ronald Bodley Scott, eds., 528-29. Oxford and New York: Oxford University Press, 1986.
- Robinson, James O. "Treatment of Breast Cancer Through the Ages." *American Journal of Surgery* 151 (1986): 317-33.
- Rodning, Charles B. "Coping with Ambiguity and Uncertainty in Patient-Physician Relationships: I. Leadership of a Physician." *Journal of Medical Humanities* 13 (Summer 1992): 91-101.

- \_\_\_\_\_. "Coping with Ambiguity and Uncertainty in Patient-Physician Relationships: II. Traditio argumentum respectus." *Journal of Medical Humanities* 13 (Fall 1992): 147-56.
- \_\_\_\_\_. "Coping with Ambiguity and Uncertainty in Patient-Physician Relationships: III. Negotiation." *Journal of Medical Humanities* 13 (Winter 1992): 211-22.
- Selzer, Richard. "A Question of Mercy." *New York Times Magazine* (22 September 1991): 32-33, 36, 38.
- Simberkoff, Michael S. "Ethical Aspects in the Care of Patients with AIDS." *Neurologic Clinics* 7 (November 1989): 871-82.
- Simpson, M et al. "Doctor Patient Communication: The Toronto Consensus Statement." *British Medical Journal* 303 (1991): 1385-87.
- Singleton, Kathleen A, and Rosemary Dever. "The Challenge of Autonomy: Respecting the Patient's Wishes." *Dimensions of Critical Care Nursing* 10 (May/June 1991): 160-61, 166-68.
- Tannock, Ian. "Treating the Patient, Not Just the Cancer." *New England Journal of Medicine* 317 (1988): 1534-35.
- Waterworth, Susan, and Karen A Luker. "Reluctant Collaborators: Do Patients Want to be Involved in Decisions Concerning Care?" *Journal of Advanced Nursing* 15 (August 1990): 971-76.
- Whitcomb, Michael E, and Daniel C Tosteson. "Medical Education in the Context of the Changing American Health Care System." In *Perspectives on the Health Professions*, ed. Edward H O'Neil and Diane M Hare, 52. Durham, NC: Pew Health Professions Commission, 1990.

## GOVERNMENT DOCUMENTS

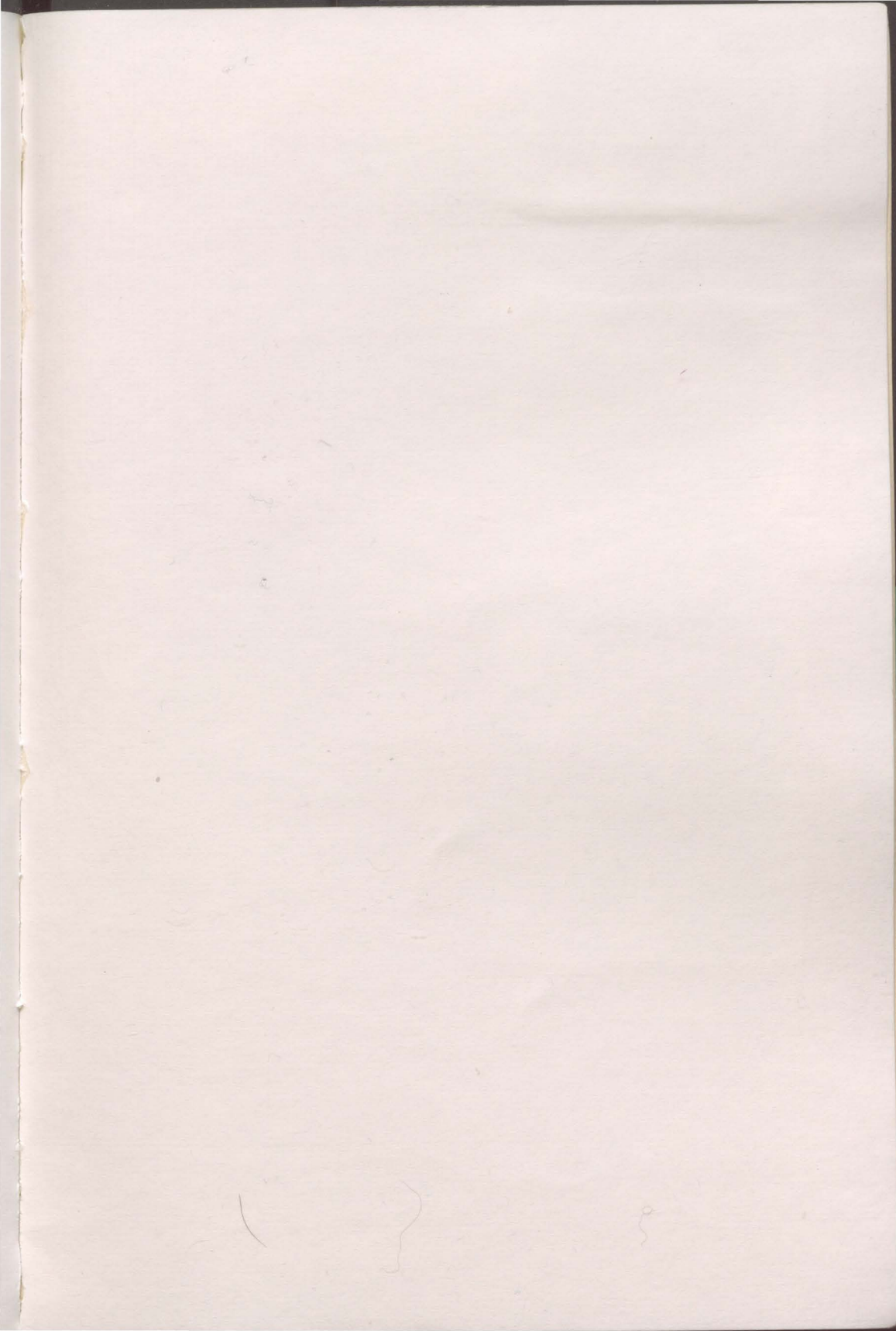
- Canada Law Reform Commission. *Human Dignity and Genetic Heritage*. 1991.
- \_\_\_\_\_. *Toward a Canadian Advisory Council on Biomedical Ethics*. 1990.
- \_\_\_\_\_. *Sanctity of Life or Quality of Life in the Context of Ethics, Medicine and Law*. 1979.
- Canada National Council on Bioethics in Human Research. *Legal Aspects of Research and Clinical Practice with Human Beings*. 1992.
- Canadian Royal Commission on New Reproductive Technologies. *Proceed with Care: The Final Report of the Royal Commission on New Reproductive Technologies*. Canada Communication Group Publishing: Ottawa, Ontario, 1993.



## 54 *Suggested Further Readings*

United States Preventive Services Health Task Force. *Guide to Clinical Prevention Services: An Assessment of the Effectiveness of 169 Interventions*. Baltimore, MD: Williams and Wilkins, 1989.

World Health Organisation, Regional Office for Europe. *Women and Occupational Health Risks*. Euro Reports and Studies: Copenhagen 1983.







3 1862 014 869 271  
University of Windsor Libraries

DATE DUE

---

~~RETURNED~~  
APR 6 1997

~~RETURNED~~

~~RETURNED~~ 1998

~~RETURNED~~  
7/10/98

~~RETURNED~~

MAR 29 1999  
~~RETURNED~~

~~RETURNED~~ 000

  
UNIVERSITY OF  
WINDSOR

LEDL  
CIRC  
R  
727.3  
.E96  
1996