

The Boston Women's Health Book Collective and Our Bodies, Ourselves: A Brief History and Reflection

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This article offers a brief history of *Our Bodies, Ourselves*, the landmark book about women's health and sexuality first published in 1970, as well as the Boston Women's Health Book Collective, its author and sponsor of numerous women's health initiatives. The organization's transition from a small, grassroots collective to a non-profit organization working at both the domestic and international levels is briefly discussed, including the development of a more diverse board and staff. Past accomplishments and current concerns of the global women's health movements are described, including some of the larger advocacy organizations now active in the women's health field. Collaboration with feminist physicians over the past two decades is also noted.

Our Early History

The history of *Our Bodies, Ourselves* (OBOS) and the Boston Women's Health Book Collective (BWHBC) began in the spring of 1969 at a women's liberation conference held in Boston. At a workshop on "Women and Their Bodies," we discovered that every one of us had a "doctor story," that we had all experienced feelings of frustration and anger toward the medical maze in general, and toward those doctors who were condescending, paternalistic, judgmental, and uninformative in particular. As we talked and shared our experiences, we realized just how much we had to learn about our bodies, that simply finding a "good doctor" was not the solution to whatever problems we might have. So we decided on a summer project: we would research our questions, share what we learned in our group, and then present the information in the fall as a course "by and for women." We envisioned an ongoing process that would involve other women who would then go on to teach such a course in other settings.

In creating the course, we learned that we were capable of collecting, understanding, and evaluating medical information; that we could open up to one another and find strength and comfort through sharing some of our most private experiences; that what we learned from one another was every bit as important as what we read in medical texts; and that our experiences frequently contradicted medical pronouncements. Over time these facts, feelings, and controversies were intertwined in the various editions of OBOS.

When we began this work, our ages ranged from 23 to 39, and we focused heavily on reproductive health and sexuality, new issues in the second wave of feminism. As we revised subsequent editions of OBOS, we included more material on such topics as environmental and occupational health, menopause and aging, often at the behest of readers and with outside help. At this writing, those of us in the original group range in age from our late 40s to our mid-60s, and one of our original members, Esther Rome, has died of breast cancer.

In the 1970s, we worked together in "cottage industry" mode at home or in libraries, often meeting together around our kitchen tables. In 1980 we consolidated our books, articles, and correspondence in a rented office and began to hire women not part of the original Collective to do cataloging and to help with other tasks. This effort marked the beginning of our Women's Health Information Center (WHIC) and two decades of networking and information sharing that has extended beyond the publication of OBOS to a number of women's health education, activist, and advocacy projects involving us locally, nationally, and internationally. We supported the founding of the National Women's Health Network—the first national women's health advocacy membership organization. We were also among the few women's organizations calling for universal health care in the 1970s, and we supported Congressman Ron Dellums' National Health Services Act, a visionary bill that included provisions for contraceptive, sexually transmitted disease, and abortion services, and access to midwives and out-of-hospital childbearing options. Internationally, we served on the Advisory Board of ISIS (an information and communication service focused on women in developing countries), distributed packets and books to health workers and groups overseas, attended global women's health meetings, and ensured, when possible, that women's groups translating OBOS would be able to reap royalties to support their work.

The founders of the BWHBC were all college educated, but a significant number of us were from working class backgrounds and were the first in our families to attend college. Some of us had professional degrees, but none of us

were in health fields. Many of us had been active in the social protest movements of the 1960s, particularly the civil rights movement, the antiwar movement, movements for women-centered childbirth and legal abortion. Some of us came from families with histories of struggle for social justice. Others of us came of age during a time of social change and found our own way to political activism. When we came together as part of a larger women's liberation movement, we were thrilled by the realization that working for social justice could affect the conditions of our lives as women. We believed that with our newfound freedom and solidarity as feminists, we could be more effective advocates on behalf of ourselves and other women, as well as other progressive causes.

Recent Growth and Development

Over the nearly three decades since the first edition of OBOS, we have continued to develop our awareness of the injustices that prevent women from experiencing full and healthy lives. As we approach the millennium, such causes of poor health as poverty, racism, hunger, and homelessness continue to disproportionately affect black and brown populations in this country and around the world. We continue to believe that effective strategies for mitigating these problems require all of us to reject the assumptions that so often hurt women of color and women who are poor. Over the years we have collaborated with women's groups both in the United States and abroad to ensure that the priorities for the women's health movement reflect the needs and concerns of all women. We also recognize the importance of supporting the leadership of women of color and low-income women within our own organization as well as in the larger women's health movements. Although this is a difficult challenge for many groups founded originally by white women, we believe that our ultimate success as a movement depends on respectful collaboration at many levels.

BWHBC's own structure has evolved over the years. We began as a collective, a circle of 12 women who met weekly and grew together both personally and politically, raising our own consciousness about health and sexuality as we reached out to inform others. We took no profits from sales of the books, using the royalties to support women's health projects and eventually to start our own WHIC and advocacy work. As soon as we hired staff who were not authors of the book, the BWHBC was not formally a collective anymore, although the board (mostly original authors for many years) and the paid staff each worked in a largely collaborative manner.

As the staff grew, so did organizational tensions and the need to develop a different model of management. For the past four years, the board of directors—now a more diverse group than it was originally—worked closely with a variety of consultants to shape a structure for the BWHBC that would introduce mechanisms of accountability that are consistent, dependable, and consonant with feminist principles. The organization now has a unionized staff (including a signed union contract) and formally designated leadership positions that operate in quite a different manner from the earlier years.

During the past few years a major revision of OBOS was also produced, *Our Bodies, Ourselves for the New Century* (May 1998). For this edition we expanded even more our efforts to include other women whose backgrounds and experiences are different from the original co-authors in terms of race, class, ethnicity, geographic origin, and sexual/gender identity. This experience helped us to develop an even greater appreciation for the challenges facing any organization working across differences, many of which have the potential to separate us.

BWHBC's Role in the Global Women's Health Movement

Within five years of its first publication, OBOS became a bestseller first in the United States, and then internationally (more than 4 million copies have been sold to date). Almost 20 foreign-language editions have been produced, including Japanese, Russian, Chinese, Spanish, French, Italian and German versions. Women in Egypt produced an Arabic book modeled after OBOS, as women are now doing in French-speaking Africa. More projects are underway today in Asia, Eastern Europe, and Armenia. At the 1995 NGO Women's Forum in Beijing, many of the women working on these translation/adaptation projects came together to compare notes and to share strategies for dealing with problems such as government censorship and fundraising.

In all editions of OBOS, we have encouraged women to meet, talk, and listen to each other as a first step toward bringing about needed change. Over the years, we have developed a number of fruitful collaborations with women's groups in different countries and have attended almost all the international women and health meetings that have been convened since the first "International Conference on Woman and Health" held in Rome in 1977. The activism

of women's health groups across the globe has been spurred by the advent of email and the Internet, and we are excited to be part of a growing web of organizations working on such issues as breastfeeding, maternal mortality, and environmental health hazards.

One continuing concern of the current global women's health movement has been the growing trend, especially among environmental groups, to label population growth as a primary cause of environmental degradation. It would be a serious step back if this trend were to lead to more overly zealous family planning programs driven by demographic goals rather than by women's reproductive health needs. We believe that the unethical and growing use of quinacrine, a sclerosing agent, and a means of nonsurgical sterilization in countries such as Indonesia, India, Pakistan, and Vietnam, represents the very "population control" mentality that has so often been destructive to women's health. Thus, we have joined activists around the globe in protesting the use of quinacrine.²

We also collaborated with such other groups as the Women's Global Network for Reproductive Rights (Amsterdam), the International Reproductive Rights and Research Action Group (IRRRAG), and WomanHealth Philippines to sponsor "The Double Challenge," a well-attended workshop series at the Beijing NGO Forum in September 1995. The brochure for this series stated:

Women from around the world face a formidable challenge. On one side are the fundamentalists led by the Vatican; on the other is the population establishment. Both are vying for control over women's sexual and reproductive lives. While the fundamentalists outlaw contraception and abortion, the populationists push new reproductive and contraceptive technologies.

The Continued Need for a Women's Health Movement^{3,4}

The concerns that brought women together several decades ago to form women-controlled health centers, advocacy groups, and other educational and activist organizations largely remain. Women are still the major users of health and medical services, for example, seeking care for themselves even when essentially healthy (birth control, pregnancy and childbearing, and menopausal discomforts).⁵; Because women live longer than men, they have more problems with chronic diseases and functional impairment, and thus require more community- and home-based services. Women usually act as the family "health broker": arranging care for children, the elderly, spouses, or relatives, and are also the major unpaid caregivers for those around them.⁶

Although women represent the great majority of health workers, they still have a relatively small role in policy making in all arenas. Despite increases in the number of women physicians, they also have a limited leadership role in US medical schools, where women represent less than 10% of all tenured faculty.⁷; Women face discrimination on the basis of sex, class, race, age, sexual orientation, and disability in most medical settings. Many continue to experience condescending, paternalistic and culturally insensitive treatment. Older women, women of color, fat women, women with disabilities, and lesbians routinely confront discriminatory attitudes and practices, and even outright abuse.⁸

Women usually find it difficult to obtain the good health and medical information necessary to ensure informed decision making, especially for alternatives to conventional forms of treatment. This problem is intensified for poor women and for those who do not speak English, in part because their class, race, and culture increasingly differ markedly from those of their health care providers.⁹

Many women are subjected to inappropriate medical interventions, such as overmedication with psychotropic drugs (especially tranquilizers and antidepressants), questionable hormone therapy, and unnecessary cesarean sections and hysterectomies, although managed care has reduced the rates of unnecessary surgery in some places. The medical care system has been slow to recognize the importance of preventive and routine care, as well as the need for more rigorous study of alternative (nonallopathic) approaches to women's health problems that have not responded well to conventional forms of treatment.¹⁰

Despite enormous advances for women over the past two decades, ongoing gender bias in public and private settings continues to relegate women to a separate and unequal place in society. We must have a strong community of women's organizations to assist women individually, to articulate women's needs, to advocate for policy reform,

and to resist the more destructive aspects of corporate medicine. Organizations such as the National Women's Health Network, the National Black Women's Health Project, the National Latino Health Organization, the National Asian Women's Health Organization, and the Native American Women's Health Education Resource Center, to name just a few, could play a key role in insuring that lay and consumer voices are part of any larger women's health debate. The inclusion of such groups by the office of Women's Health Research at the National Institutes of Health already has enriched discussions concerning research affecting women.

Ironically, except in a handful of states, poor women on Medicaid can obtain a federally funded sterilization but not a federally funded abortion. This limitation has led some women to "choose" sterilization because they have so few options. As the women's health movement continues to emphasize, without access to all reproductive health services, there can be no real choice in matters of childbearing.

Over the years, the BWHBC has collaborated with physicians who have shared the feminist perspective represented in OBOS. One such colleague, Mary Howell, MD, (more recently known as Mary Raugust), died from breast cancer in February 1998. The author of a popular 1972 book entitled *Why Would a Girl Go into Medicine?* and the first woman dean at Harvard Medical School, Mary contributed to the research that resulted in a legal ruling forcing medical schools to eliminate female quotas. These informal quotas had kept the female presence in medical schools well below 20 percent of the total number of students since the turn of the century. She remains for us one of the finest role models for women in medicine, and we hope that her speeches and writings will be published to inspire the younger generations of female physicians. Another physician, Alice Rothchild, MD, has written and spoken eloquently about her experience as a feminist obstetrician-gynecologist, and we have made her 1997 AMWA speech available at our website.¹¹

Members of the media often ask us if we think that progress has been made in addressing the concerns women have had about medicine. We believe that physician awareness of condescending and paternalistic behaviors that are now generally regarded as disrespectful elsewhere in society has been heightened. It also appears that more women feel that their physicians take their concerns seriously, rather than dismissing their complaints with "it's all in your head." But other problems have been exacerbated, and although not unique to women, women's more frequent contact with the medical care system means that women confront these issues much more regularly than men do.

Many managed care plans have contributed to reductions in access to care, especially good quality care, for some women. They have, for example, not allowed some physicians to provide needed treatments. Sometimes, physicians have not had the time to adequately assess the plethora of new drugs and medical technologies that they regularly recommend to patients. Cutbacks in local community services and public health programs make it harder to sustain an emphasis on preventive health care.

The BWHBC has a special interest in such problems as the increasing influence of right-wing organizations over public policies affecting women's health, the explosion of health and medical technologies marketed primarily to women, the objectification of women's bodies in the media, the exclusion of consumers from policy setting and oversight functions in many managed care plans, and the relatively few sources of noncommercial information about women and health, especially with a well-informed consumer perspective. We recognize institutional racism as a continuing problem exacerbated by the fact that most caregivers and health care administrators come from economic, social, racial and ethnic backgrounds quite different from those of the people they are serving. Finally, we believe it is critical to challenge the tendency to over-"medicalize"¹² women's lives and turn normal events such as childbearing and menopause into disabling conditions requiring medical intervention.

As the women's health movement moves into the next century, the ability to build broad coalitions will largely determine the political effectiveness of women's health care advocates. We can learn much, for example, from the passage of the Americans with Disabilities Act, which succeeded in large part because the disability rights community reached out to form broad alliances with other groups not initially aware of the universal impact of this legislation. Finding common ground and ways to bridge racial, ethnic, and class difference in particular, will be among the great challenges we face.

Early Accomplishments of the Women's Health Movement

Here are just a few snapshots:

In the early 1970s, lack of information about birth control pills and a growing awareness among women about problems associated with their use led to organized protests, including disruption of special hearings in Congress conducted by Senator Gaylord Nelson. Fortuitously, Barbara Seaman, author of *The Doctor's Case Against the Pill*,¹³ and Alice Wolfson met at the Nelson hearings; several years later they co-founded the National Women's Health Network with Dr. Mary Howell, Belita Cowan, and Phyllis Chesler, Ph.D. One important result of women's efforts to obtain more and better information about oral contraceptives (as well as other drugs) was the introduction of the Patient Package Insert (PPI) program at the FDA (Food and Drug Administration). A related struggle involved the provision of PPIs for so-called estrogen replacement therapy. Not long after PPIs appeared for estrogen products, the Pharmaceutical Manufacturers Association joined the American College of Obstetricians and Gynecologists to sue the FDA in an effort to block the distribution of PPIs for estrogen products. In response, four women's and consumer organizations, led by the National Women's Health Network, entered the case as co-defendants and filed an amicus brief cogently arguing for the right to such basic information. And we won. PPIs for estrogen products were retained through the late 1970s, although later suspended by the Reagan Administration. The Clinton Administration has reinstated them in a different form.¹⁴

Sterilization abuse, a longstanding problem for poor women in the United States, became the focus of a government inquiry after activists, journalists, and community organizations documented and publicized the degree to which certain women, especially women of color and Native American women, were sterilized without informed consent.¹⁵ This happened in a variety of ways: some women agreed to be sterilized without fully understanding what it meant, especially when information was given in terminology they did not understand; others were told that their public welfare benefits would be denied unless they agreed to sterilization; some were told that the procedure was reversible, when, of course, that was not true. Special hearings resulted in regulations, written in part by both consumer and physician health activists, designed to curb the incidence of abuse among federally funded sterilizations. These regulations included a 30-day waiting period, the provision of information in a language clearly understood by the woman, and prohibition of hysterectomy solely for the purpose of sterilization. Though far from perfect, these regulations have been somewhat effective.

As early as the mid-1970s, the women's health movement addressed controversies surrounding breast cancer. For many years the standard practice of US doctors, in doing a breast biopsy and finding malignant tissue, was to proceed immediately with a mastectomy. Several years of hard work during the 1970s, especially on the part of activist and journalist Rose Kushner, who has since died from breast cancer, resulted in a landmark recommendation by the National Cancer Institute that breast biopsies be performed as part of a two-step procedure in most cases. The panel advised that a diagnostic biopsy specimen be studied with permanent histologic sections before offering various treatment options to a patient with breast cancer. This recommendation represented an important step forward in the treatment of breast cancer and also increased general awareness of the importance of nonsurgical treatments.

During the 1970s dozens of women-controlled health centers emerged as alternatives to the conventional delivery of health and medical care. Many were organized nonhierarchically with physicians having little or no policy-making roles. Most offered self-help groups that taught cervical self-exam, abortion services that were often the only ones in the region, and support groups for dealing with such experiences as premenstrual problems; infertility, and menopause. They also pioneered a more thorough, client-centered approach to informed consent. Several women among the founders of the Feminist Women's Health Centers pioneered the development of a menstrual extraction technique that has since been used by women in other countries. In large part because of these women-controlled health centers, abortion became firmly established as an outpatient service. In 1992 only 7% of abortions were performed in hospitals, while in 1973 more than half

of all abortions had been performed in hospitals.¹⁶ This assured that first-trimester abortions in this country would be appropriately demedicalized.

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<http://www.ourbodiesourselves.org/about/jamwa.asp>

The Boston Women's Health Book Collective (now known as Our Bodies Ourselves) is a non-profit organization founded in 1969 whose board members include Teresa Heinz Kerry, Susan Love, and Gloria Steinem. Their mission is to empower women by providing information about health, sexuality, and reproduction. Our Bodies, Ourselves is the organization's core vehicle for driving their mission. While OBOS is famous for its voice in policy, advocacy, and educational efforts related to women's health, they see their role as a global content provider as paramount. We are delighted to present Our Bodies, Ourselves—an in-depth look at women's sexuality and reproductive health, from the first gynecological exam to sexual health in our later years. The history of "Our Bodies, Ourselves" and the Boston Women's Health Book Collective (BWHBC) began in the spring of 1969 at a women's liberation conference held in Boston. At a workshop on "Women and Their Bodies," we discovered that every one of us had a "doctor story," that we had all experienced feelings of frustration and anger toward the medical maze in general, and toward those doctors who were condescending, paternalistic, judgmental, and uninformative in particular. As we talked and shared our experiences, we realized just how much we had to learn about our bodies, that simply finding