

# Transforming doctor-patient relationships

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- Boston Women's Health Book Collective. *Our Bodies, Ourselves*. New York, NY: Simon and Schuster, 1973.

Historians often ponder how books change history. *Our Bodies, Ourselves*, the enormously popular and influential work, will long be studied for igniting and sustaining a worldwide women's health movement. It should also be studied for how it transformed doctor-patient relationships and why it is such a trusted source of health information.

The book began in a small discussion group on 'women and their bodies' at a Boston women's conference in 1969. It grew into a course on women and their bodies and finally into a book with global appeal.<sup>1</sup> Between 1973 and 2005, the Collective published seven English language and two Spanish language editions in the USA and over 20 foreign language editions. Within five years of its first publication it was a bestseller, and by 1999 had sold over four million copies.

In her history of the women's health movement, Morgan argues that it would be difficult to exaggerate the impact of *Our Bodies, Ourselves*. It filled the void where there existed few popular books on women's health. Many colleges, universities and medical schools adopted it as a text.<sup>2</sup> It was unique in that it gave voice to women's own experiences of reproductive health and body issues. Elevating and validating women's experiential knowledge, the Collective broke new ground in medical communication. The authors urged women to demand answers and explanations and to insist on enough information to negotiate the health care system. They envisioned creating a new type of partnership between patient and doctor that bore almost no resemblance to the model that existed. In the new model, it was envisioned that doctors and patients would have different responsibilities with the latter having ultimate control.

*Our Bodies, Ourselves* evolved through a dialogue whereby ordinary readers communicated with the Collective to get information, lodge concerns and complaints, and suggest revisions to the book. The Collective was urged to add information relevant to an ever-growing array of 'people like me'. As they corresponded with their readers, they enhanced cover-

age for women with disabilities and women of colour, weathered tumultuous storms over how to address lesbian health issues, and expanded the scope and coverage of a growing array of issues. Kline's research on letters from women to members of the Collective during the 1970s and 1980s details how critical a role readers played in the evolution of this work.<sup>3</sup>

Finding ways to include many voices and yet retaining control over the final product posed many challenges. Invited contributors and people who corresponded sometimes had conflicting views on what was important. Keeping the book affordable was always at odds with expanding coverage. Editorial effort increased exponentially. For the 2005 edition, editors Judy Norsigian, Heather Stephenson and Kiki Zeldes managed and coordinated the work of 102 contributors and hundreds of 'voices' with the help of a 'tone and voice editor' and a photo editor.

The evolution of *Our Bodies, Ourselves* is visible in the front matter of each edition. For example, the preface to the 25th Anniversary Edition, written by feminist luminaries Byllye Avery, Helen Rodriguez-Trias and Gloria Steinem anchored the volume in a continuation of second wave feminism.<sup>4</sup> The current edition takes a very different approach. Reaching out to a new generation of women for whom second wave feminism is history, not lived experience, the front matter includes only a brief 'Introduction'. A short letter from the founders tells readers that the history of the book is available on the web.

How has the content evolved? The 1973 edition focused heavily on women's changing sense of self in response to the second wave of feminism. It encouraged women to change internalized sexist volume covered the anatomy and physiology of reproduction and sexuality, the social and cultural aspects of sexuality and relationships, and included a controversial chapter written by a Boston gay collective that was replaced in later editions. Short chapters on nutrition, exercise, rape, self-defence, venereal disease, birth control, abortion, deciding about having children and child-bearing were followed by a limited discussion of the menopause. A well-formulated critique of the American health care system rounded out the 275-page paperback that sold for \$2.98, but with substantial discounts to clinics and women's groups.

The 2005 edition, an 832-page encyclopedic version, opens with chapters on body image, eating well, drugs, exercise, complementary health practices, emotional wellbeing, environmental and occupational health, and

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violence and abuse against women. Expanded sections address relationships and sexuality, sexual health, reproductive choices and childbearing, and over 170 pages are devoted to growing older and to medical problems and procedures. The companion website provides breaking health news, as well as the history of the book.<sup>5</sup> For women living under conditions of censorship, web-based information supplements what can be published or promoted locally.

The organization itself has changed. The book is no longer produced by a collective but by an incorporated entity with a board and a unionized staff. What has not changed is a commitment to validating women's personal experience and organizing for change. The accolades continue to pour in. Bylle Avery, founder of the National Black Women's Health Project, has called it the 'bible for women's health' and the *Journal of the American Medical Association* has hailed it as 'A mother lode of information and resources for the client/consumer and the physician'.

How did it come to be such a trusted source? Bell's account of how editions were painstakingly updated to translate scientific information into health information for women shows how committed the Collective was to producing evidence-based information.<sup>6</sup> But the success of the book really lies in the powerful combination of presenting solid evidence framed in terms of self-determination, patients' rights and social justice through women's own voices. Women's experience, not professional opinion, made this groundbreaking volume so powerful. While its appeal has always been its usefulness as a source of personal health information, it continues to confront the politics of women's health. By producing a personal health manual that doubles as an organizing tool, it has been able to retain its core values and feminist principles even as it became institutionalized.

The organization's global impact continues to grow from working collaboratively with women's groups worldwide to developing local editions that are far more than translations.<sup>7</sup> Twenty-one adaptations have been nurtured around the globe, each reflecting the social and cultural conditions of women in different countries. It has inspired groups in Tibet, Senegal, India, Denmark, South Africa and Egypt to develop similar types of books that put health knowledge directly into the hands of women.

The Collective, along with other self-help health and consumer groups that emerged in the late 1960s, played a critical role in transforming patients from passive recipients of health care into active consumers. Today's concept of shared decision-making in health care is firmly rooted in the principles and practices of health communication set forth in *Our Bodies, Ourselves*. Scholars now debate which patients prefer being active decision-makers and even ask if passive patients should be urged to take more active roles in decision-making. These controversies reflect the diffusion of models of doctor-patient communication and relationships that the book set out to create over three decades ago.

As health care in the USA has changed, *Our Bodies, Ourselves* has attempted to suggest how to manage those changes. For example, because primary care visits are largely limited to 15 mins, with insufficient time to resolve many of women's most pressing issues, the book suggests that women improve doctor visits by bringing in their own information or even an advocate. A new ideal model of the doctor-patient relationship is also evolving. A woman's voice in the current edition tells readers, 'Friends now marvel at my close relationship with my current doctor and my ability to talk back, question, and disagree with him and his colleagues. He respects me and trusts me to tell him what is going on, and I, in turn, trust him to listen, make suggestions, and consult with me before any action is taken'. As elusive as this type of relationship may be to many, if not most women, its inclusion suggests an evolving model of health communication that was unimaginable when the book first appeared.

Looking back over 35 years, it has retained its core strategy of providing the best available evidence accompanied by women's own voices. It has also earned the distinction of being a trusted source of information. That trust is deeply embedded in the organization's steadfast refusal to accept funding from the pharmaceutical industry or other sources that would create conflicts of interest. This sets it apart from many of the newer, highly professionalized women's health advocacy groups that have flourished from such infusions of resources.<sup>8</sup> As one of a small number of women's health organizations that has survived beyond the active phase of the second wave of feminism,<sup>9</sup> *Our Bodies, Ourselves* continues to be a source of trustworthy health information for women. As such, it is well worth another look.

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