

The Legacy of Midwifery and the Women's Health Movement in Contemporary Discourses of Patient Choice and Empowerment

Margaret E. MacDonald, PhD

ABSTRACT

This commentary traces the roots of the notion of patient empowerment and patient-centred care to the radical beginnings of the women's health movement and the feminist critiques of medicalized childbirth. I pay particular attention to the emergence of the concept of informed choice in community midwifery as one of the women's health movement's key strategies to combine medical science with women's own experience to effect the empowerment of women in health care. I also reflect on the limitations of the notions of empowerment and choice as they have been taken up by mainstream health institutions and the health care marketplace—often without acknowledging the contributions of midwifery and the women's health movement—noting the diminished promise and potentially problematic effects of taking these notions out of their political contexts.

KEYWORDS

women's health, midwifery, informed consent, patient empowerment

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L'héritage de la pratique sage-femme et du mouvement pour la santé des femmes dans les discours contemporains sur le choix et l'autonomisation de la patiente

Margaret E. MacDonald, PhD

RÉSUMÉ

Dans le cadre du présent commentaire, les origines des notions d'autonomisation de la patiente et de soins centrés sur la patiente remontent aux débuts radicaux du mouvement pour la santé des femmes, ainsi qu'à la critique féministe de l'accouchement médicalisé. J'accorde une attention particulière à l'émergence du concept de choix éclairé dans l'exercice de la profession de sage-femme comme exemple de stratégie clé du mouvement pour la santé des femmes, qui visait à allier la science médicale à l'expérience personnelle des femmes pour favoriser leur autonomisation dans le secteur des soins de la santé. Je réfléchis également aux limites des notions de choix et d'autonomisation, depuis leur récupération par les principaux établissements de soins de santé et par le marché des soins de santé, en insistant sur leurs promesses atténuées. Je souligne enfin les effets potentiellement problématiques liés à l'appréhension de ces notions hors de leur contexte politique.

MOTS-CLÉS

santé des femmes, pratique sage-femme, consentement éclairé, autonomisation de la patiente

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INTRODUCTION

Long before the Canadian Medical Association created the Charter for Patient Centred Care, and long before the head of genomic research in the US uttered the words “patient empowerment,” the Boston Women’s Health Book Collective published the first edition of *Our Bodies Ourselves*. The year was 1970. The Boston Women’s Health Book Collective (BWHBC) was the vanguard of the North American women’s health movement and *Our Bodies Ourselves* (OBOS) introduced several new ideas into the public discourse on health that were revolutionary at the time: that one can and should learn about and be responsible for one’s body and health, and that with access to information and a sense of responsibility would come personal strength, autonomy, and a more critical stance towards health providers and institutions.

The goal of this commentary is to reflect on the significant contributions of the women’s health movement to present-day discourses of ‘patient empowerment’ and ‘patient-centred care’ – what many are calling a paradigm shift in mainstream medicine and some are positioning as the ultimate fix for health care systems in both the United States and Canada. I argue that the roots of the contemporary notion of patient empowerment lie in the radical beginnings of the women’s health movement and the feminist critiques of medicalized childbirth. Yet this history is often weakly represented or missing altogether from contemporary discussions and historical treatments of the topic. The concept of informed choice in midwifery is of particular interest here not only because I am writing for a midwifery audience, but because choice was the rally cry of the early days of the women’s health movement and it remains central both as a political agenda and a clinical principle for midwifery. Not only have the feminist roots of current concepts of patient empowerment and patient-centred care often been overlooked, but the concepts themselves have been transformed in problematic ways. Thus, this commentary will also reflect on the limitations of patient choice and empowerment as the new health care imperative.

The Roots of Patient Empowerment

In the 1960s women and other marginalized groups had much to gain from transforming their relationships with doctors and the health care system: medicine was male dominated and paternalistic, abortion was illegal in most American states and Canadian provinces, many jurisdictions prohibited the distribution of birth control information to unmarried women, and women delivering in hospital could expect to labour alone without husbands or support persons and be subjected to a series of unproven medical interventions over which they had little say. The women’s health movement coincided not only with major social changes of the era but with a significant moment in the history of science and biomedicine as well: the ‘new alterability of human reproduction’ made possible by synthetic hormones, most notably in the form of the birth control pill.¹ It was a time of great possibility and change.

Study groups and self-help clinics were mainstays of the early years of the movement: how-to instructions for vaginal self-examination at home, how to buy and use urine tests to detect pregnancy, how to talk to your

Margaret E. MacDonald
is Associate Professor
in the Department of
Anthropology at York
University in Toronto,
Ontario.

doctor about breast cancer treatment options, how to give birth at home. Women were producing and sharing knowledge about their own bodies, performing technical procedures, employing techno-scientific equipment and information, and meticulously recording what they observed. *OBOS* was on hand, assisting women in these personal and collective projects to become lay experts on their own bodies and the clinical disciplines that attended them.² Although we may tend to think of the women's health movement as synonymous with critiques of biomedicine and medicalized childbirth, the credo of the BWHBC was in fact to merge the most current, reliable scientific knowledge with self-knowledge and advocacy.² It was this combination of evidence and experience framed in terms of patients' collective rights and social justice that made *OBOS* so unique and useful to women. *OBOS* had a profound effect on mainstream medicine, as historian Sheryl Ruzek writes (p.182),

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*.³

Informed Choice in Community Midwifery

Community midwifery as a social movement in the 1970s and 1980s was an excellent example of the *OBOS* credo of combining medical science with women's own experience to effect the empowerment of women in health care. Clients entered into egalitarian relationships with midwives in which information and decisions were shared. Though midwives made good rhetorical use of the dichotomy of natural versus medical birth, community midwives rarely eschewed medical science and technology entirely. In fact they relied on it for their own education [in combination with other modes of training].⁴⁻⁸ Nor did the pursuit of natural birth preclude the informed and judicious use of scientific knowledge and biomedical technology.^{4,6}

Indeed community midwives were pioneering their own 'feminist techn-scientific experiments'¹ around birth: teaching themselves anatomy and biology, having clients self-administer glucose test-strips during pregnancy, and using simple devices, birth positions, and manual manoeuvres to aid labour and delivery.

The concept of 'informed choice' had a dual role in the midwifery movement; it was both a political tool and clinical principle. Documents called Informed Choice Agreements were distributed by midwives to potential clients to inform them about their clinical philosophy and qualifications, as well as the legal standing of the profession locally; they also specified the midwife's expectations of the client's conduct and responsibilities.^{5,7,9} At a time when there was no legal profession of midwifery in Canada and the prospect of such was met with deep skepticism by medical providers and authorities, the Informed Choice Agreement was a political tool for midwives to self-credential and also to advocate for midwifery on the basis of a woman's right to choose her caregiver. Midwifery legislation in Canada did not come about because politicians and policy makers cared about women's embodied knowledge and dismantling the doctor-patient hierarchy, but because it fit with an emerging culture of health consumerism in the late 20th century. The rhetoric of a consumer's right to choose her caregiver was fundamental to the success of midwifery professionalization campaigns across North America.^{4,6,10,11}

As a clinical principle, informed choice was the realization of one of the women's health movement's ideals: midwives trusted women to know their own bodies best and expected them to take responsibility; clients were empowered by sharing information and decisions with their care provider. Since midwifery's incorporation into the formal health care system in several provinces in Canada over 20 years ago, mainstream health care providers and policy makers have had the opportunity to observe the success of the midwifery model of care both in terms of its appeal among patients and its excellent clinical outcomes.¹²⁻¹⁵ Indeed the midwifery model of care, with informed choice and a vision of empowerment for clients at its centre, has become a model for mainstream health reform.

Patient Empowerment Today

The notion of patient empowerment and choice has become mainstream. It has been taken up by most major medical associations and exhorted in federal reports on health systems reform throughout the United States and Canada.¹⁶⁻²⁰ The Society of Obstetricians and Gynaecologists of Canada, for example, now includes the terms 'informed choice' in its mission statement.²¹ Though there is no single definition, the paradigmatic features of patient empowerment in mainstream medicine are that patients are expected to manage their own health by making 'healthy lifestyle choices' and actively engage in medical encounters by informing themselves, asking questions, and choosing wisely among various treatment options. For their part, physicians, hospitals and other providers are expected to create the conditions for patient empowerment and choice by taking the time to offer understandable medical information and listening to patient concerns and questions. The concept speaks generally to a rebalancing of power between doctor and patient.¹⁶ A 2001 report by the Institute of Medicine's Committee on the Quality of Health Care in America, for example, defined patient-centred care as "providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions".¹⁷ Such documents often speak to timely treatment and consent, and outline specific complaints processes, but they also re-position the patient as someone with values and rights that must be respected. Patient empowerment may also include patient access to and participation in their own medical records.²⁰

The notion of patient empowerment is typically traced to the history of informed consent laws in the US and patients' rights movements of the 1970s and can be defined as the ethical obligations of physicians to disclose clinical information to patients in a way that patients can adequately understand. The function of informed consent is to protect the autonomy of the patient and one's right to exercise control over one's body. Assuming a direct line from informed consent' to patient empowerment—as much of the patient empowerment literature seems to do—skips over the important contributions of the

women's health movement and the political nature of the concept of informed choice. Further, while informed choice in midwifery shares some common ground with the principle of informed consent in mainstream medicine, there are some significant differences.

First, while informed consent is fundamentally an ethical-legal principle whose origins lie in medical science, informed choice is an inherently politicized notion that, while in part a reaction to the lack of truly informed consent in medicine¹⁹ took shape outside science and medicine in the intimate spaces of midwifery and the women's health movement. Informed choice was never intended as an add-on to clinical care but emerged (and persists) as one part of a fundamentally different way of caring.⁴

Second, in practical terms, informed consent is circumscribed by the way that medicine is typically practiced—short appointments, doctor-patient hierarchy, and limited continuity of care—while informed choice is facilitated by the other features of midwifery care: the non-hierarchical midwife client relationship, long appointments, continuity of care.⁴

Third, what counts as authoritative knowledge in informed consent versus informed choice in midwives care differs; with the former, patients listen to health care providers impart 'evidence' and clinical options to them in an accessible way and then must make a choice; the latter involves this too but midwives also grant authority to other kinds of knowledge – a woman's own knowledge, feelings, and past experience about her body and previous pregnancies as well as her lifestyle and moral orientation.

Fourth, there is a difference between informed choice and informed consent in the degree to which 'autonomy' is the ultimate goal. Informed choice does indeed perform well when put to the bioethical tests of "autonomy, competence/capacity, disclosure, voluntariness, beneficence and nonmaleficence"²²—so there is good reason for feminist scholars today to represent informed choice as the pursuit of autonomy. But an overfocus on autonomy elides what I understand to be the cultural project of informed choice in midwifery since the start: to transform models of the body and care in the reproductive process.

It must also be noted that the rise of patient empowerment and choice is deeply entwined with other aspects of the contemporary health landscape: the burgeoning field of complementary and alternative medicine, the epidemic of chronic diseases that require new levels of self-monitoring and care, the ubiquity of Direct to Consumer (DTC) drug advertising, the availability of health information on the internet, and a massive increase in the availability of biomedical goods and services to be used at home without medical supervision. In short, the culture of consumption infuses the contemporary health care trend towards personal choice and empowerment.

How Empowering is Patient Empowerment?

The logic of patient empowerment and choice in the biomedical realm is that knowledge itself is power and will lead to greater patient satisfaction, better compliance with treatment, and better outcomes. Yet there are several limitations and cautions worth noting in this mainstreamed push towards informed choice and patient empowerment.

First, a limitation. The rhetoric of patient empowerment through knowledge and the exercise of choice assumes that all health consumers have the time, ability, and confidence to freely choose among various attractive routes to self-knowledge and treatment, when in fact people are constrained by time, personal resources, and structural barriers. Many people lack access to primary care physicians for lack of health insurance [in the US], or even in systems of socialized medicine, for lack of time due to work or childcare responsibilities, for lack of proximity to clinics and hospitals, or for lack of resources to pay for extended benefits. Others may experience barriers of literacy, culture, race or citizenship status. Such social and economic inequalities within communities shape health consumption decisions and can severely limit one's 'options'. A home diagnostic test or an OTC medication, for example, can fill in and save a shift worker or busy mother time—and perhaps even a job—by giving them the means to quickly confirm and treat a condition at home. But the convenience, privacy, and sense of control in this kind of health consumption are not free of anxiety or risks.

Consumers must choose a product, use it correctly, and assess the accuracy of the results. For those who lack the time, patience, or skill to carry out these steps, this work may not be a choice but a burden or a last resort. Imagine the user of a home pregnancy test who is a minor, and for whom a positive result would not be welcomed, who feels she cannot visit a physician because the jurisdiction in which she resides has parental information laws, or the only health care provider in town is a family friend or relative. A positive test result for her would be the beginning of a cascade of decisions that may be far from empowering. The promise of consumer choice and patient empowerment for such individuals can involve a kind of work and responsibility that not everyone is able or prepared to take up with pleasure and confidence. Ultimately, the benefits of consumer rhetoric to solve social problems of access and equity is unevenly felt.

Second, a critique. Patient empowerment in the era of the patient-consumer fits well with what social science scholars call 'responsibilization'. It is an aspect of what Michel Foucault called 'biopower': a means by which state institutions govern us by getting us to govern ourselves.²³ As good citizens we are supposed to manage our lifestyles, minimize risky behaviour, appear for regular medical check-ups, and follow treatment protocols for the sake of our own good health and, in Canada, for the sustainability of the public health care system. It's not that avoiding risk and making well-informed healthy choices is a problem, but that 'responsibilization' can blame the individual sufferer for his or her condition and obscure significant sources of ill health – such as workplace stress, poverty, environmental contamination, or limited access to the range of 'healthy choices' we are supposed to be making. Those who appear to have failed to take up this new health imperative to become empowered patients may be stigmatised as uninformed, non-compliant, as threats to themselves and others.

Third, a reflection. The current rhetoric of patient empowerment in mainstream medicine is quite different from that imagined and practiced by the BWHBC and the social movements of midwifery in the 1970s and 1980s. The empowerment imagined in mainstream medicine today is individualized,

not collective, and the focus is on choices and information, not consciousness-raising. Picture the purchaser of a genetic profile from the private genomic scanning provider 23andMe—a company that claims that “knowledge is power” and that individuals can “improve their lives” through knowing their own genome²⁴—receiving their results in the comfort of their own home, bearing the burden and interpretation of the information without support or expertise. Consciousness-raising, on the other hand, envisioned in feminist terms, involves sharing one’s experience with others and the development of a set of goals or visions for the transformation of society,²⁻³ rather than receiving personalised information as the basis upon which to make individual choices. The rhetoric of empowerment today seems to be all choice, no consciousness-raising—a far cry from the kind of exchange and care between patient and provider imagined and practiced in midwifery.

CONCLUSION

In this commentary I have described how the notion of informed choice emerged in community midwifery and came of age in the push for professional status. I have also described how the formerly radical notions of choice and empowerment have been taken up by mainstream health institutions and marketplaces today and, in the process, have been recast in terms of individuals and personal information rather than collectives sharing experiences and defining political goals. Yet midwifery as a profession, and many midwives as individual providers, remain committed to the social change agenda that infused the movement from its inception. Forty years ago *OBOS* recognised not only choice but access to choices as a pressing concern², and in midwifery today, access, diversity and inclusion have clearly emerged as new social movement goals.²⁵⁻²⁷ Midwives are pursuing these goals in a number of ways: by reaching out to marginalised communities, by holding spots for immigrant women likely to come late to care, by encouraging diversity in their own ranks, by recognising the need for greater cultural competence and sensitivity as practitioners, and by continuing to advocate for systemic changes in order to challenge a status quo in which some women have choices and others don’t, and in which some women are cared for better than others.²⁷

In other words, midwifery in Canada today continues to pursue what Dutch philosopher of medicine Annemarie Mol would call a political ‘logic of care’ in an era otherwise consumed by the new ‘logic of choice’.²⁸

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