# Beyond Medical and Academic Agendas: Lay Perspectives and Priorities

Vivienne Walters
McMaster University

ABSTRACT

One theme in the feminist literature on women and health concerns the social processes involved in the medicalization of women. Another major emphasis is on the social aetiology of disease. Neither of these approaches has emphasized women's own perspectives and priorities. In this article, the author outlines some neglected research issues and considers the role of medical, academic and lay perspectives in the formulation of policy.

RÉSUMÉ

Un thème dans le discours féministe au sujet des femmes et la santé s'occupe des processus sociaux en jeu dans la médicalisation des femmes. On accorde aussi une importance particulière à l'étiologie sociale de la maladie. Aucune de ces façons de s'y prendre ne met l'accent sur les perspectives et les priorités des femmes elles-mêmes. Dans cet article, l'auteure présente quelques sujets de recherche négligés et examine le rôle des perspectives médicales, scolaires et profanes dans la formulation de la politique.

SURPRISINGLY, DESPITE THE INCREASING strength of the women's health movement, almost no attention has been paid to developing a representative picture of women's own health priorities (Kaufert, 1988). The recent wave of needs assessments regarding women have typically focused on reports of "key informants," as well as morbidity and mortality rates. There are similar gaps in the sociological literature as well, which has often neglected lay perceptions and experience (Clarke, 1985; Cockerham, 1988; Fox, 1984; Pirie, 1988).

This paper starts with a brief review of work on women's health, noting the main types of themes and the relative lack of interest in lay concerns.[1] The discussion serves as an introduction to the second section which outlines research issues with respect to women's perspectives and priorities regarding their health. The final sections pose questions about what information should be taken into account in the formulation of policy and how it might incorporate medical, academic and lay perspectives.

## Medicalization and its Critique

One major theme in the literature has concerned the social construction of women's health, with a particular emphasis on the medicalization of women's lives and their increasing subjection to medical dominance (Ehrenreich & English, 1979; Riessman, 1983). The critique is a familiar one. A range of women's experiences have come under the

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attention of medicine; among the central foci have been childbirth (Oakley, 1984; Wertz & Wertz, 1977), menopause (Fausto-Sterling, 1985; Kaufert & Gilbert, 1987; McCrea, 1983), eating disorders (Currie, 1988; Lawrence, 1987; Orbach, 1986) and mental illness (Penfold & Walker, 1983; Stoppard, 1988; Walker, 1984). Problems faced by women have been defined as requiring medical intervention or surveillance, and perhaps more critical, what is normal has been rendered pathological. The narrow model of biomedicine has been severely criticized for its very partial understanding of women's health. When physicians have stepped beyond the confines of biology, they have often labelled women's problems as psychogenic (Clarke, 1983), thereby invalidating women's accounts or blaming the victim. A variant of this approach focuses on problems in the psycho-social development of women. For example, rape, sexual abuse and violence against women have been explained in terms of women's supposed masochism (Caplan, 1987; Fausto-Sterling, 1985; Masson, 1985). In addition, the process of medicalization has been criticized for the dominance characteristic of the doctor-patient relationship and for the medical monopoly of information. The relationship is not one that emphasizes communication or participation; compliance is valued (Ruzek, 1986).

Another part of the literature explores the social, economic and political bases of women's ill health and lays the basis for a "feminist epidemiology" (Doyal, 1979; Kaufert, 1988). This does not necessarily provide an explicit critique of biomedicine, but does develop an alternative perspective by showing ways in which illness is socially produced. Studies within this tradition provide a different conceptualization of illness, using gender as one basis for the development of social structural explanations. The premise is that, to an extent we can barely appreciate as yet, women's health reflects their subordination as it is manifested in the conditions of their lives. It is not a well developed area of the literature, given that we appear to have placed primary emphasis on the social *construction* of health.

In contrast, this perspective tends to take as given certain indices of ill health and the challenge is to understand how these conditions are socially *produced*. Studies have established associations between women's health and social class (Brown & Harris, 1978; Doyal, 1979; Graham, 1984; Perales & Young, 1988; Walters, 1980) and their experiences in the paid labour force (Brown & Harris, 1978; Lowe, 1989; Lowe & Northcott, 1988; Messing & Reveret, 1983; Stellman, 1977; Tierney, Romito & Messing, 1990). The importance of women's familial roles and experiences is also captured in a number of ways: domestic labour can be hazardous to health (Doyal, 1983; Rosenberg, 1984); so too the number and age of children at home (Brown & Harris, 1978; Tierney, Romito & Messing, 1990), the structure of the family and women's support networks (Bernard, 1976; Brown & Harris, 1978; Graham, 1984), family violence (Penfold and Walker, 1983) and housing (Doyal, 1983; Gabe & Williams, 1987). The nature and importance of these influences will also vary through the life cycle (Gee & Kimball, 1987; Lewis, 1985). However, we have neither good documentation of the social bases of women's ill health nor a well elaborated theoretical framework. While more attention is being paid to the social determinants of health—witness the current emphasis on lifestyles and health promotion—whether researchers and policy makers are fostering a truly social (as opposed to an individualistic) understanding of the sources of illness is unclear.

Thus there is a dominant though well critiqued medical model and the beginnings of an alternative "feminist epidemiology" which emphasizes gender, and features of the social and economic position of women. Yet what is often missing from both of these models is a sense of women at the centre of the analysis. In the literature on women and medicalization, women were first seen as victims of an emergent male medical profession (Ehrenreich & English, 1979). A more recent theme has recognized women as actors and looked at them as "collaborators" in the process (Riessman, 1983)—seeking medical interventions which then have had

unanticipated negative consequences. However, even though there has been a growing interest in women's involvement and experiences, research has generally not allowed women's own priorities to emerge, and we do not know whether and how these priorities vary. We have only scattered information on what women identify as their foremost health problems and what they consider to be the source of these problems. While there is a tradition of research on lay concepts of health (Currer & Stacey, 1986; Calnan, 1987; Eyles & Donovan, 1990; Stacey, 1988), it often has not addressed the issue of gender. While critical of medicine for assigning the patient a relatively passive role, the feminist literature has not necessarily been more successful in incorporating lay perspectives and priorities.

To some extent the perspectives and priorities of "ordinary" women are ignored. Others argue that lay concerns cannot necessarily be taken at face value. For example, Brown and Harris (1978) note that, while lay experiences are important—and they do base their analysis on women's accounts of their illness and aspects of their lives—the researcher has the task of transcending these and imposing his or her own view. The researcher will face multiple perspectives and there will also be limits to what respondents are willing to talk about and what they are able to articulate (as in Cornwell's [1984] distinction between public and private accounts). Moreover, Brown and Harris (1978: 273) argue that "the world is capable of having an impact irrespective of the meanings a person brings to it."

In a similar though more political vein, Jaggar (1983) quotes arguments that women's views may represent a false consciousness, shaped by hegemonic ideology.

> [T]he standpoint of women is not expressed directly in women's naive and unreflective world view ... women's perceptions of reality are distorted both by male-dominant ideology and by the male-dominated structure of everyday life. The standpoint of women, therefore, is not something that can be discovered through a survey of women's existing beliefs and attitudes—although such a survey should identify certain commonalities that might be incorporated eventually into a systematic representation of the world from women's perspective. (Jaggar, 1983: 371)

Particularly in work that consciously claims a feminist label, such views seem to represent an uneasy ambivalence. On the one hand, medicine is criticized for expert dominance and not hearing women's voices, yet we appear to have been reluctant to go out and listen. Even when we do listen, we seem to doubt what credence can be attached to lay perspectives—especially when they do not coincide with accepted political dogma. Within this criticism lies an academic or political agenda which seems uncomfortably reminiscent of the dominance of medicine. (The only virtue we can claim is a relative lack of legitimacy, which limits the potential for dominance.)

I hasten to add that this is not to argue that the voices of women have been discounted in the feminist literature. Even a casual review of recent research uncovers important work on women's concerns and experiences regarding pre-menstrual syndrome (Pirie, 1988), pregnancy and childbirth (Oakley & Graham, 1986), reproductive issues in general, including menopause (Martin, 1989), mental illness (Miles, 1988) and cancer (Clarke, 1985). Yet this research still provides us with only a partial view of women's perspectives and priorities. It has concentrated on specific issues which have been selected by researchers themselves rather than being generated by an understanding of women's own priorities. Moreover, it has perpetuated the very emphases we have criticized in medicine. The focus has often been on women's roles in generational reproduction—pregnancy, childbirth, premenstrual syndrome, menopause. Less attention has been devoted to daily reproduction, including the care of children and dependent adults. (With cutbacks in health and social services and increases in life expectancy, this role may well be increasing, with negative consequences for women's health [Aronson, 1990; Graham, 1985].) Another often neglected aspect of women's lives is their role as wage workers, including the hazards they face in the workplace. We have few studies which look at women's concerns regarding their occupational health and safety (Lennon, 1987; McDaniel, 1987;

Walters & Haines, 1990). Almost no attention has been paid to women's concerns with respect to health problems that are not gender specific. Neither have we developed a good understanding of how these health issues are intimately linked with class, race and ethnicity.

**Research Issues**

The strong emphasis on medicalization in the feminist literature leads us to ask to what extent this is reflected in women's own understanding of their health. In what respects is biomedicine reflected in women's views of the nature and source of their health problems? Research on lay concepts suggests that people blend several different models of understanding (Martin, 1989; Pill & Scott, 1986; Stacey, 1988; Williams, 1984) and that biomedical imagery is only one element. The effects of medical dominance on women's own perspectives and health/illness behaviours may be less pronounced than we have supposed, as Kaufert and Gilbert (1987) have suggested with respect to menopause, Gabe and Calnan (1989) in their work on women's perceptions of medical technology, and Martin (1989) regarding reproductive issues.

There are other reasons, too, for anticipating incomplete medicalization—though it is impossible to assess how this has varied over time and whether the impact of medical models has in fact diminished. Struggles against patriarchal structures have centred on women's control over their bodies, their reproductive roles and the attributes they have been assigned by medicine. In recent decades, the women's health movement has given added voice to these struggles and has provided an alternative ideology, legitimizing women's own experiences, challenging medical dominance and explaining women's health in terms of their subordination. Is this perspective reflected in women's own concepts of health and illness? Do they see their health in social terms, particularly in relation to the structure of their lives? Do they understand their illness in terms of the social and economic dimensions of their lives? Do they, for example, link the quality of their health with their social class, family structure, number and age of children, whether they are caring for dependent adults, their social isolation, the resources upon which they can draw, and the nature of their paid work, if they are employed? These aspects of women's lives have all been associated with women's health; do women themselves make such links?

By locating women's views in relation to these alternative explanatory models, it is impossible to assess ways in which health/illness is a source of gender consciousness. At the same time, health and illness experiences may be linked with other structures of subordination—class, race, ethnicity, for example—and may be a basis for the development of a consciousness of structured inequalities. Blaxter (1983) and Cornwell (1984) have shown that the ways in which people think about their health and the causes of illness are linked to their social class. Martin (1989) has also highlighted the importance of race. Not only do we need to know more about such variations in perceptions, we should also ask whether women themselves explicitly make these links—whether class or gender consciousness, for example, is expressed through or arises from understandings of health and illness.

In a more descriptive and practical vein, we know very little about women's own priorities. What health problems do women experience and what do they consider to be the main ones? What types of problems do women worry about, even if they have not actually experienced them? Do they have preoccupations about their future health status? Why is it that some problems are accorded a greater weight than others? How do they affect women's lives? What do they symbolize? What do they see as their central needs for help? How might policy better reflect the problems they face? Underlying all these questions there is also the issue of what women define as health problems. Where do they draw the bounds of what may be labelled as health/illness, rather than social or economic or interpersonal problems? At present we know little about women's own views.

**Policy Issues**

To pose such questions also leads us to consider what part women's own perspectives and priorities should play in the formulation of policy

agendas. It prompts us to reflect on the types of information on which policy might be based and resources allocated.

Provincial governments have shown an increasing concern with the development of health policy with respect to women. In Ontario, for example, there have been policy initiatives regarding birthing centres, the recognition of midwives, the introduction of a breast cancer screening programme, the establishment of a Women's Health Bureau to advise the government on policy, as well as commitments of funds to a range of projects such as sexual assault centres, halfway houses and detox centres. What is not clear and barely discussed, however, is the best method to determine priorities for the allocation of funds.

The traditional methods of establishing priorities rely on mortality and morbidity data, though the validity of using mortality data as an index of health needs has long been questioned. They provide but a partial account of the health of the living and focus our attention only on the major causes of death. Morbidity data are also of limited value insofar as they reflect use of services and tell us little about unmet needs—problems which do not reach the health care sector or which are not dealt with adequately. The use of such data has also been criticized because they reflect only medical definitions of disease. Exactly the same criticism can be levelled at the willingness of policy makers to rely on the opinions of medical experts, who can speak from experiences not captured by mortality and morbidity data. Health surveys have counteracted these problems to some extent by looking at self-reported health, but these data can still be interpreted within a primarily medical framework and do not necessarily convey women's own priorities or their dissatisfaction with health services. They indicate the prevalence of health problems, but do not indicate which of these concerns preoccupy women most. Seldom are women asked about their satisfaction with the care they receive.

An alternative approach, which has been accorded greater legitimacy in recent years, has involved the recognition of lay representation of women through the women's health movement and various other community-based special interest groups (Federal/Provincial/Territorial Working Group on Women's Health, 1990). Such initiatives increase participation and extend the sphere of debate. Yet this lay input may also be misleading. Often the input comes from key informants who may be non-medical service providers or leaders of women's groups. Even when a broad range of input is invited, only the best organized groups, the most articulate and those with the most resources are usually in a position to prepare briefs and make submissions to the State. So even though steps have been taken to increase community representation, we still have a less than clear understanding of how "ordinary" women define their health needs and how such definitions vary among women.

One study that has raised some of these issues and sought to develop an additional method of identifying women's health needs is an Australian study by Redman et al. (1988). She and her colleagues surveyed a representative sample of women in an Australian community, asking them about their main health concerns. Several interesting patterns emerged. Women's personal priorities and concerns differed from those identified as government policy priorities. They also differed from what has often been a dominant theme in other discussions of women's health—aspects of their reproductive roles—a theme emphasized not only by medicine but also, as noted above, by much of the feminist literature on women and health. Being overweight and low-level psychological problems were the main concerns women voiced.

Preliminary results from a survey of women in Hamilton, Ontario, indicate similar patterns: among the health problems which bother women most are stress, arthritis, being overweight, migraines/chronic headaches and tiredness (Walters, 1991). Such data present a distinctive image of women's concerns. They suggest the importance of surveying women's priorities and developing better criteria to guide the process of policy making.

**Concluding Comments**

It is perhaps understandable that women's own perspectives and priorities have generally been

ignored (at best, tolerated) by medicine; this is consistent with the ideology of medicine. Ideologically, it is feminist scholarship that should have taken women's concerns as a primary focus. It is ironic that, while critical of medical dominance, we seem to have come close to asserting our own. Apart from their intrinsic academic interest, there are practical reasons for putting women's priorities and definitions of needs on our research agendas. It is only when women's concerns are documented that there is the possibility of taking them into account in policy making. No longer can physicians and other key informants and experts claim the unchallenged right to define women's needs. However, how might lay concerns be taken into account? How might they be merged with medical and academic perspectives?

To pose questions in this manner already accepts that the medical and academic perspectives have some validity. Sociology has been criticized for a too ready acceptance of the medical model (Clarke, 1985), but I think it is also possible to argue that, in the critical literature on women and health, medicine may have been too readily dismissed. Riessman's (1983) observations regarding women as active participants in the process of medicalization are useful partly because they help to underline an ambivalence towards medicine; we can both value it at the same time as we recognize its severe limitations. It is a perspective which may have been lost in our development of critiques of modern medicine; what is left unspoken is how medicine is of value. The bounds of uncertainty cannot be clearly drawn and, even within medicine, there is often no clear consensus regarding its effectiveness (Roos & Evans, 1989). Yet as Brown and Harris (1978) argue in their discussion of their reasons for choosing to use clinical definitions of depression, medicine represents a rich heritage of observation and classification. For these authors, the use of diagnostic categories does not necessarily imply anything about aetiology.

The "academic" agenda—as I have labelled the feminist literature on women and health—has made us aware of the limits and politics of medicine. It has also raised important questions about the social aetiology of mortality and morbidity. As I have already argued, this approach to the social production of illness is still very much in its infancy and requires much more attention to empirical work and the development of appropriate theoretical frameworks. While this is a task for sociology and related disciplines, it should not necessarily be wholly separate from medicine, for part of the challenge, presumably, is to understand how the social is manifested in the biological. We need to develop a strong base for a social or feminist epidemiology as well as establishing links with the insights of medicine.

This still leaves us with the question of how lay concerns fit into this amalgam of perspectives. They can be encouraged as an appropriate focus of academic research, but what of policy issues and the distribution of scarce resources? Apart from a loud collective voice that articulates women's concerns, we also need to think more carefully about how lay concerns can be given weight. In part, this requires that we consider to what extent they can be regarded as "legitimate"—something other than a focus of academic curiosity, or an aid to doctors who wish to communicate better with their patients.

For example, what significance can be attached to women's reports of tiredness as a primary health problem? Or, what credence do we give to women's concerns about being overweight? What if women do not cite major causes of death among their priorities? Do we take women's concerns at face value? Do we treat them as examples of "false consciousness"? Do we view them as an indication of lack of knowledge? In what ways can we use them as guides to policy formulation? Furthermore, if we regard different types of concerns as being more or less valid, on what basis do we make these distinctions? Insofar as the priorities of "ordinary" women differ from those of medicine and the women's health movement, how might these be reconciled and merged? What criteria should guide the process of policy formulation?

As scholars we might well look more closely at such aspects of the social construction of health-related needs and the ways in which different needs are articulated. Also, we could more self-consciously consider our own location in these processes.

## NOTE

1. My primary focus here is on feminist scholarship. This tends to neglect the work of the substantial lay component of the women's health movement. Yet, as I will argue, even lay organizations may only partially reflect women's concerns.

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Parlor has a heat climbs onto sundry levities. My father's coma
quietly dismissed mood ring. Ninety bucks an hour to lose grace
appropriate to context. Opportunists have survived on milk and
bread with touch alone to magnify depletive chaperones. I romp
some hours I sleep. Some mood is gentian. Also a parental.
Here we are together focused on abuse of one's free time. More
mention of the duty to be damned. The loose affiliation tangent
to a southern drawl learned young unequal to a speech impediment.
Basement smell, my learning about feelings. Planned things
motivate redundancy. A pattern shields a pattern shields
conscience from pattern. Now my father hopes he can remember who
he is changes. We remember for him what consists of seeing how
we think. Products of former thinking.

Mashed potatoes, window dressing, shapes with definition

*Sheila E. Murphy*
*Phoenix, Arizona*