

**IS THERE A METHOD TO THIS MADNESS?
STUDYING HEALTH CARE REFORM
AS IF WOMEN MATTERED**

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Abstract

As the health care system has undergone significant reform and restructuring in recent years, researchers have turned their attention to studying the effects of these changes. A primary focus of attention is the economic consequences of health care reform, but some research addresses the consequences of health care reform for providers and recipients of care as well. Remarkably, however, little of the extant research focuses on women who are, in the majority of cases, the frontline workers (in institutions and in the home), and who are using (or wanting to use) various health services. In describing clinical studies, Rosser concluded that women are “overlooked, ignored or subsumed” (Rosser 1994). This is also an apt description of most research on health care reform. This paper examines the limitations of current research and considers what research on health care reform would look like if women mattered. The paper focuses on questions related to epistemology and methods (i.e., what kinds of questions should we be asking? what are the data requirements to capture the effects of health care reform on women users and providers of health care? etc.), and suggests strategies for researchers and those in the policy sector to ensure that the evidence base on which policies and practices are designed is appropriate and inclusive.

IS THERE A METHOD TO THIS MADNESS? STUDYING HEALTH CARE REFORM AS IF WOMEN MATTERED

Introduction

Canada's health care system has undergone significant restructuring in recent years, and researchers have been studying the effects of government "reforms" on the provision of service, health care workers (i.e., their work process and their health), and recipients of care (i.e., their health and their satisfaction with care). Yet, little research done to date has focussed on women's experiences, either as providers or recipients of care. We do not know about the differences between women and men, and we know even less about the differences amongst women, when it comes to paid and unpaid work in the system, or the effects of health care system restructuring on the quality and nature of the care individuals receive. Research conducted for the National Coordinating Group on Health Care Reform and Women¹ (Armstrong and Armstrong 1999; Bernier and Dallaire 1999; Fuller 1999; Gurevich 1999; Howard and Willson 1999; Botting, Neis et al. 2000; Scott, Horne et al. 2000) suggests that women have, to a very large extent, been "overlooked, ignored or subsumed" (Rosser 1994) in studies into the provision of health services and the effects of health care reform on providers and recipients of care. Consequently, it is difficult to ascertain exactly what consequences flow from the increasing privatization of health care, or even from changes in how health care is organized and delivered in various jurisdictions around this country.

That there are such tremendous gaps in the research on the health care system (and health care reform in particular) is both troubling and surprising. The preponderance of workers in the field of health

¹The National Coordinating Group on Health Care Reform and Women is an initiative of Health Canada's Centres of Excellence for Women's Health Program. The Group includes Pat Armstrong (York University/National Network on Environments and Women's Health), Carol Amaratunga (Maritime Centre of Excellence for Women's Health), Jocelyne Bernier (Centre d'excellence pour la santé des femmes), Karen Grant (University of Manitoba/National Network on Environments and Women's Health), Kay Willson (Prairie Women's Health Centre of Excellence), and Ann Pederson (British Columbia Centre of Excellence for Women's Health), as well as policy staff from Health Canada (Lynne Dee Sproule, Manager, Centres of Excellence for Women's Health and Diane Poneé, Director, Women's Health Bureau).

care are women (Armstrong and Armstrong 1996), and women provide a substantial amount of home-based care (Cranswick 1997). As well, women utilize health services more extensively than men because of their greater likelihood to engage in preventive health maintenance, and because of the nature of the conditions affecting women and those for whom they provide care (Kandrack, Grant et al. 1991; Macintyre, Hunt et al. 1996; Pollard and Hyatt 1999). In a climate where the inclusion of women in research is more or less expected (and in the U.S., it is mandated by law), it is curious that most research on health care continues to neglect women as a key population or fails to analyse data for gender effects (Stewart, Cheung et al. 2000; U.S. General Accounting Office 2000).

The gaps in the research literature on health care reform are also surprising given the great (some would say, renewed) interest in demonstrating effectiveness and efficiency in health care. Now framed as a evidence-based medicine, clinicians are urged to apply the “best” clinical evidence (informed by rigorous scientific research) to make decisions about diagnosis and treatment (Willis and White 1999). This same type of thinking is expanding to other areas of health (and social) care intervention. Service providers are implored to consider efficacy and risks first and foremost. The influence of payers (including the state) means that consideration of the costs and “value added” associated with health (and social) care services must also be considered. An economic rationalist philosophy is clearly in place. Evidence-based decision-making is seen as a way to ensure a more rational allocation of resources, and perhaps a strategy to reduce the overall state contribution to health care (or to stretch those resources further).

Yet, one might reasonably ask whether there is adequate evidence to justify the various reforms that have already been implemented, particularly since so much of the research fails to examine women’s experiences. Eichler, in a recent report for Health Canada’s Women’s Health Bureau, observes that “More than ever before, evidence-based decision-making is a fundamental principle of federal government action. Therefore, getting our facts right is critical. Research that is gender biased is by definition poor research” (Eichler n.d.). Furthermore, we should inquire as to whether the measures we use to assess outcomes adequately capture what we need to know about health care reforms and interventions.

It is these gaps in the research literature on health care reform that have prompted The National Coordinating Group on Health Care Reform and Women to interrogate how we do research in health care. The aim of this paper is to examine several key issues about researching health care reform, and then to propose ways to do research on health care reform as if women mattered. In particular, the following topics will be discussed: the prevailing approach in research on health care (with a particular focus on evidence-based medicine/evidence-based health care); the socially constructed nature of data and the vexing question of what counts as evidence; how we operationalize key variables in the study of health and health care (e.g., what does health care reform mean and how is it different from health care system restructuring, etc.); and the implications of these various epistemological and methodological issues for research on health care. Throughout the paper, research questions that require further study specifically related to the effects of health care reform on women are identified. The overall aim is to find a way for researchers from different disciplines and orientations to develop research approaches to inform health care policies that yield evidence that is sound and inclusive.

Researching Health Care and Evidence-Based Medicine: Everything That's Old is New Again

There is now a long tradition of experimentally-based research in health which has been (and is) used to show the efficacy of treatments. "Experimentalists," if we can use this term, have advanced the notion that the only clear way of establishing the effectiveness of treatments is through the use of the randomized controlled trial (RCT). This is where individuals are randomized to treatment or control groups, a treatment is administered through a blind procedure, and objective measurements are used to assess the clinical effectiveness of an experimental treatment. The argument holds that "ceteris paribus" (all other things being equal), changes found post-treatment provide an indication of the effect of the new treatment over an existing treatment or placebo. The RCT is held up as the only way to make a definitive claim as to clinical efficacy (McKinlay 1979).

One of the clearest expressions of support for the RCT came in Archie Cochrane's landmark publication Effectiveness and Efficiency (Cochrane 1972). Guided by the knowledge that many medical

measures had had little, if any, impact on the health of individuals (McKeown and Lowe 1966; McKeown 1976), Cochrane asserted that no intervention should be employed without a clear demonstration of clinical effectiveness. McKinlay went one step further, arguing that “government should not support through public funding for general public use, any service, procedure, or technology, the effectiveness of which has not been or cannot be demonstrated (McKinlay 1979, p. 551).

The centrality of the RCT in medicine is now taken for granted. We cannot imagine the introduction of new drugs without rigorous controlled clinical investigations. Even surgical procedures and techniques are expected to have studies of their clinical effectiveness (Bunker, Barnes et al. 1977). For example, it was a clinical trial that demonstrated that patients with myocardial infarction could be cared for safely at home, and not just in cardiac or intensive care units (Mather 1976). Other studies using the RCT design have demonstrated the efficacy of nursing homes and day surgery (Newell 1992), and even the effects of social support in maternity care programs (Oakley 1990), among many other health services.

The RCT has not only shaped how research is done on clinical effectiveness; it has had an enormous influence over the entire body of research in health. This is because the RCT is held up as the quintessential method of investigation – the gold standard against which all other methods are measured. Cast as mere “observational” studies, other research methods (and studies) are seen as the lesser cousins to the RCT. Even where a number of observational studies suggest that a treatment works (as in case studies that so commonly pepper the pages of journals such as the New England Journal of Medicine), such findings will very likely be quickly dismissed for their failure to control the study conditions, and their inability to isolate the definitive causal connection between variables. The principle of “ceteris paribus” simply cannot be satisfied (Daly and McDonald 1992). Even still, observational studies are widely used in health care research. They provide important data regarding such things as the state of individuals’ health and their use of health care services, and they are often the seedlings for future innovations in treatment.

The influence of the RCT has been profound. The Cochrane Collaboration, established in 1993, maintains a database of reviews of RCTs that cover all areas of health care (<http://www.cochrane.org>).

The Campbell Collaboration, established in 2000, maintains a similar database that focusses on social and educational experiments (<http://campbell.gse.upenn.edu>) (Oakley 1999). Australia's National Public Health Partnership has proposed a framework for evaluating public health interventions (Rychetnik and Frommer 2000). This schema is specifically designed to avoid the pitfalls of applying the methods commonly used in evidence-based medicine in the assessment of public health interventions which traditionally do not employ experimental methods, and which often are affected by social, environmental, and political contexts beyond the control of the researcher.

A number of "Evidence-Based" journals have been established, offering "the best empirical evidence" to those individuals involved in clinical practice, and in policy, management and related fields (e.g., Evidence-Based Medicine, Evidence-Based Health Care, and Evidence-Based Nursing). The Centre for Evidence-Based Medicine even offers an explicit rank ordering of levels of evidence, accompanied by grades of recommendations (<http://cebm.jr2.ox.ac.uk/docs/levels.html>). At the pinnacle, of course, are systematic reviews of research based on RCTs or other methods in which there is "homogeneity." In other words, the reviews are "free of worrisome variations (heterogeneity) in the directions and degrees of results between individual studies."

While reviews of RCTs are seen as the scientific basis of clinical practice, the RCT method is not without its own problems. Can a researcher eliminate all competing hypotheses? Can the results in a carefully designed RCT be replicated in "the real world," that is, to all individuals who would use a particular treatment and not just to those who satisfy strict eligibility criteria for a RCT? Can efficacy determined in the short term period of a study stand up to the test of time in the longer term? What about the ethics of conducting a RCT? Is it appropriate to withhold a potentially beneficial treatment from some, and give them a placebo instead? Is this method appropriate outside of investigations of the clinical effectiveness of drugs and medical procedures? The debate on these questions is beyond the scope of this paper, but what seems clear, at least in the world of evidence-based decision-making, is that worst-and-all, the RCT is still the preferred method of research, and the cumulative weight of empirical data derived from such systematic investigation provides a credible base on which to make decisions about the use of various interventions.

But questions about RCTs do ask us to consider the implications of using this method of evaluation. Oakley reminds us that the RCT “is [not] the *only* means to reliable knowledge, is [not] *sufficient* in itself, or is [not] *always* the right approach,” and that it should be seen “as a means to an end, and not an end in itself” (Oakley 1990, p. 193). The trouble is, however, that the RCT has become the basis for clinical evaluation studies. Even more, it is the underlying philosophy of the RCT that has been generalized, and as such the criteria for assessing what makes a good RCT are often used inappropriately to judge methods based on entirely different epistemological assumptions. With the RCT viewed as the model of how to do research, the implication is that findings based on other methods are simply deemed to be invalid and unconvincing (recall the “levels” mentioned earlier), and therefore should not serve as the basis of practice or policy.

Facts, Data, and Evidence:
Does Method Matter?

Health care research today is extremely varied, ranging from RCTs designed to evaluate the clinical effectiveness of treatments, to health services research employing population-based administrative data and epidemiological methods (e.g., case-control studies, cohort studies), as well as the full range of methods used in the social sciences (e.g., health surveys, qualitative interviews, ethnographies). Such methodological diversity is necessary in an increasingly complex health care system. But while most observers would acknowledge that the complexity of the health care system and the questions that emanate from it cannot be answered through a single approach (Grant, Adelson et al. 1999), it is also true that the preponderance of evidence upon which health practice and health policy is based still uses and privileges a narrow range of methods, and relies disproportionately on a particular kind of data. By and large, numerical data is collected using methods within the positivist/quantitative tradition which claims the virtues of objectivity, the separation of fact from value and meaning, the separation of the observer from the observed, the capacity to identify “the general laws that serve for explanation and prediction” (Lincoln and Guba 1985), and reproducibility.

Feminist critics of science have challenged the claims of positivism, particularly the notions of

objectivity and value-freedom in research (Eichler 1980; Fee 1981; Tuana 1989). Science in practice, they note, views subjectivity with suspicion, and considers itself to be devoid of values. In other words, the individual characteristics of scientists are thought to play no part in the content or conduct of science. Feminist critics of science suggest that it is not possible to separate ourselves from our work, and to view the subjects of our research separate from the contexts within which they exist. Reflecting on the biases inherent in what she calls traditional “gendered” medical research, Doyal observes that both the priorities and the techniques of biomedical research reflect the white male domination of the profession. Bias has been identified in the choice and the definition of problems to be studied, the methods employed to carry out the research, and the interpretation and application of results....There has been relatively little basic research into non-reproductive conditions that mainly affect women....Where health problems affect both men and women, few studies have explored possible differences between the sexes in their development, symptoms and treatment. (Doyal 1995, p. 17)

The neglect of women's health conditions in biomedical and other health research, coupled with the omission of women from biomedical and clinical studies means that there continue to be significant gaps in our knowledge of women's health, and this has potentially dangerous consequences in terms of both the diagnosis and treatment of women's medical conditions (Eckman 1998; Greaves, Hankivsky et al. 1999). In sum, notwithstanding protests to the contrary, it seems clear that the parameters of science are influenced by values including those based on sexism and racism (Gould 1981; Coney 1988; Riger 1992; Rosser 1994). The values of science in practice similarly influence what is researched (and what is not), and how it is studied, as well as what is considered credible evidence (Tesh 1988).

Most positivist researchers hold steadfast to the view that “there is a single tangible reality ‘out there’ fragmentable into independent variables and processes, any of which can be studied independently of the others [and] inquiry can converge onto that reality until, finally, it can be predicted and controlled” (Lincoln and Guba 1985, p. 37). Expressed in this way, the data await measurement, and the task of scientists is to find the means to gather the data. Data (facts) are not the same as evidence. Daston observes that “facts are evidence *in potentia*...only when enlisted in the service of a claim or a conjecture do they become evidence, or facts with significance. Evidence might be described as facts hammered into signposts” (Daston 1994, p. 243). At first this distinction might seem trivial, or even semantic, but as we shall see, what data are (or are not) collected, and how they are used (as evidence) are profoundly

important in the field of health care.

In the context of the current preoccupation with evidence-based decision-making, statistical data is often seen as superior to all others. Those in the positivist camp actually believe that the numbers don't and can't lie, and that individuals' accounts of their experiences (stories) are merely anecdotal and totally subjective. By contrast, those in the qualitative (and feminist) camp believe that the only way to understand everyday life is to tap into individuals' lived experiences. These researchers would argue that experience is evidence (Scott 1994). Zelditch compares the two traditions in this way:

Quantitative data are often thought of as 'hard' and qualitative as 'real and deep' – thus, if you prefer 'hard' data you are for quantification and if you prefer 'real,' 'deep' data, you are for qualitative [research]... What do to if you prefer data that are real, deep *and* hard is not immediately apparent. (Zelditch 1962)

Like Currie, I believe that there is little to be gained by framing the matter as a choice between quantitative or qualitative data – between statistics or stories (Currie 1988). It is better for us to examine critically the methodological choices we make, to assess the adequacy of the measures and data we use, and to see the ways in which different kinds of data can be productively utilized in understanding health care. Instead of “either/or,” we should adopt a “both/and” approach, with a very strong emphasis on what is most appropriate to the questions at hand. Such a critical analysis means that we should challenge all kinds of orthodoxy, whether that is in the wholesale acceptance of official statistics, population-based administrative data, and RCTs, or the valorization of subjective accounts of individuals working in or using health care services. A few examples will suffice to make this point.

Official statistics such as mortality data are often viewed as objective and beyond question, and an important indicator of the overall health of a population. Doyal argues, however, that mortality statistics are “only crude indicators of the state of health of those people who remain alive” (Doyal 1979, p. 242). According to Susser et al., mortality data cannot show the impact of disease, only the outcome of disease (Susser, Watson et al. 1985). A 1981 editorial in The Lancet simply stated that “counting the dead is not enough” (Cartwright 1983, p. 4). Decades of health research tells us that mortality statistics alone are insufficient as a barometer of the health of the population. The measures of health and morbidity, including self-assessed health status, illness experience (health conditions), and disability and

activity limitations, provide additional and essential information on the health of the population. These measures also recognize that health is more than the absence of disease; it includes physical, mental and social dimensions. In short, “morbidity rates ... modify the spectrum of disease disclosed by mortality rates” (Susser, Watson et al. 1985, p. 65).

Commentators on social statistics (medical and otherwise) suggest that official statistics reflect a particular ideological viewpoint, and often tell us more about the counters than the counted (Doyal 1979; Miles and Irvine 1979; Armstrong and Armstrong 1987). The viewpoint reflected in mortality statistics is that of medicine, a social institution, with its own culture, ideology and normative structure. That culture cannot be and is not “bracketed” in the phenomenological sense by physicians when they validate the death of an individual. Susser et al. remind us that:

Death certificates assign cause of death selected, at the best, by the subjective judgement of variously trained physicians; the certificates are coded by clerks using an unavoidably imperfect international classification of diseases; and most registration procedures lay down that in each case a single disease must be selected as the underlying cause of death, thus distorting reality, for where multiple diseases coexist and contribute to death, ordinarily only one is registered and analyzed as the cause. (Susser, Watson et al. 1985, p. 34)

My intent here is not to argue that mortality or any other official statistics are of limited or no use. Instead, I want to emphasize that these data reflect the interests, needs, and priorities of physicians and other health practitioners who provide health care, and the state which pays for health care (Doyal 1979, p. 241). Furthermore, we can discern the priorities of those who record information for official statistics

and other databases by what is recorded and what is not. Krieger puts it this way:

No data bases have ever magically arrived, ready made, complete with pre-defined categories and chock full of numbers. Instead their form and content reflect decisions made by individuals and institutes, and, in the case of public health data, embody underlying beliefs and values about what it is we need to know in order to understand population patterns of health and disease. In other words, data are a social product, and are neither a gift passively received from an invisible donor nor a neutral collection of allegedly inevitable empirical facts. (Krieger 1992, p. 413)

To complete this critical analysis of different types of data, it would be absurd to view qualitative

data as somehow fool-proof. Concerns about the validity and generalizability of qualitative data are commonly advanced by those more inclined toward quantitative measurement. Even among qualitative researchers, there are legitimate questions being asked regarding the quality of the information gathered, the adequacy of sampling, how well the researcher has been able to represent the data that has been gathered, etc. (Lincoln and Guba 1985; Mays and Pope 1995; Fitzpatrick and Boulton 1996; Poses and Isen 1998; Oakley 1999; Giacomini, Cook et al. 2000; Giacomini, Cook et al. 2000; Mays and Pope 2000). Researchers using qualitative methods clearly need to use rigorous means of gathering data, and careful, reflexive analysis techniques.

It is also worth remembering that while qualitative approaches can be extremely helpful in some areas of investigation, they are not necessarily the most appropriate techniques in all areas of investigation. DeVault points out that feminist researchers often use qualitative methods because these approaches facilitate a certain kind of “excavation” work that helps to bring women’s experiences into view (DeVault 1999). At the same time, she notes that quantitative methods can and do accomplish this same goal, and may at times be necessary. This is a view shared by Oakley whose recent work involving RCTs and other quantitative methods have left some in the feminist research community puzzled, to say the least. Reflecting on her experience using different kinds of methods, Oakley asserts that Women and other minority groups, above all, need “quantitative” research, because without this it is difficult to distinguish between personal experience and collective oppression. Only large-scale comparative data can determine to what extent the situations of men and women are structurally differentiated. (Oakley 1999, p. 251)

Appropriate methods and data, whether quantitative or qualitative, clearly are what we need as we try to understand health and health care. We must know when to use which methods. We would do well to remember Einstein’s astute observation that “not everything that counts can be counted and not everything that can be counted counts.” Given our current focus on a broad definition of health and health care, we can ill afford to overlook any valid source of data, and we may actually need to consider *different* and *multiple* sources of information to understand health and health care in their complexity.

Missing in Action: Where are the Women in Health Care Research?

To this point, the focus of this paper has been fairly general. Now, I want to turn more specifically to research on health care, health care reform and women. Where are the women? Are they missing in action?

The simple answer is – yes, the women are missing. For decades, women were largely excluded from medical research. Their omission from clinical research was often justified on grounds that women's menstrual cycle would interfere with the observed effects of drugs being tested, because women were potentially pregnant, or on the argument that the incidence of certain diseases was too small to justify their inclusion (Melbourne District Health Council 1990; Rosser 1994). In addition, many medical researchers held steadfast to the belief that research done on men could be generalized to women, and therefore there was no need to study women separately or comparatively. The absurdity of this type of thinking has led to studies on the effectiveness of diet pills using samples of male subjects even though the majority of users of this product are females, and a study of breast and uterine cancer, where the researchers were considering the effects of particular nutrients on estrogen metabolism, and they chose male subjects in the belief that estrogen metabolism is similar in men and women (Cotton 1990; Cotton 1990; Dresser 1992; Mastroianni, Faden et al. 1994; Mastroianni, Faden et al. 1994; Nechas and Foley 1994).²

In the U.S., to remedy this situation, the National Institutes of Health Revitalization Act of 1993 (Public Law 103-43) was enacted and it required the equitable inclusion of women in clinical studies. A recent report of the U.S. General Accounting Office, and a Canadian study by Stewart et al. confirm that change has been very slow in biomedical research, that women continue to be under-represented in clinical investigations, and that researchers do not adequately explore gender effects even when they do

²Messing shows that many studies on occupational cancers exclude women (Messing, 1998). The rationale that is offered is that women are less likely to get occupational cancers. But women do get occupational cancers (e.g., ovarian and breast cancer among chemical workers, leukaemia and ovarian cancer among hairdressers, etc.). Recent research suggests that women are indeed extremely sensitive to certain environmental carcinogens in the workplace, particularly when there are specific "windows" in development of organs such as the breast. Chemical threshold levels are set based on the typical 180 lb. white male and may seriously overestimate the levels of exposure at which chemicals harm women's health.

include women as well as men in their study samples (Stewart, Cheung et al. 2000; U.S. General Accounting Office 2000).

As the research of The Coordinating Group shows, the problem of missing women does not only relate to clinical studies. In fact, in the broader area of health research, women are invisible as well. Women have a huge stake in health, as patients, providers, and decision-makers. Women constitute the majority of health care workers, and women themselves use health services extensively, or assist others in accessing health services. To capture the range of women's involvement in health care, Graham refers to women's roles as "providers, negotiators and mediators" (Graham 1983). Even though women are so integrally involved in health care, their absence from most research in this area continues.

Researchers would be hard-pressed to justify excluding women from health care research on biological grounds (as has been done in clinical research). The problem in health care research is less often one of exclusion than one of making the women invisible (Kaufert 1999). This is often done in the course of data analysis, particularly in research of a more epidemiological nature. For example, consider the research from the Manitoba Centre for Health Policy and Evaluation (MCHPE). Research at this centre (but certainly not only at this centre) only rarely examines the differences in health experiences between women and men (Metge, Black et al. 1999). The majority of studies report age and sex-standardized findings using a population-based health information system (Brownell and Hamilton 1999; Brownell, Roos et al. 1999; DeCoster, Chough Carriere et al. 1999; Roos and Shapiro 1999). While it is true that standardization or adjustment of population-based data has the virtue of calculating a single rate that adjusts for each age and sex group of a standard population, thereby resulting in improvements in the comparability of rates of different populations, such global statistics do not permit us to see the specific ways in which health experiences (whether we are talking about mortality or utilization) manifest differently in the various subgroups of a population. We need sex-disaggregated data (Horne, Donner et al. 1999) if we are to begin to understand the gendered nature of health and illness experiences, including those related to health care utilization.

But even additional studies that involve the calculation of sex-specific statistics remain limited in their capacity to capture why and how sex/gender matter in the study of health and health care. It is

simplistic to treat the biological variable sex as if it can capture the full array of social, political, and economic forces that both structure and produce (ill) health for women and men, or explain the effects of policy changes on individual providers and recipients of care. Indeed, it is important for researchers to examine not just sex as a demographic characteristic that, for example, affects susceptibility to disease, need for surgery, or likelihood of accessing health care. We also need studies on the influence of gender, and this involves examining relationships of power, and subordination and superordination.

Decades of research make clear that **both sex** (i.e., the biological differences between women and men) and **gender** (i.e., how femininity and masculinity are constructed in and by society, thereby influencing individuals' definitions of themselves and their behaviours) are central to understanding health, disease, and disability, as well as individuals' experiences in the health care system (Greaves, Hankivsky et al. 1999). In various studies conducted in Canada, the U.S., and around the world, sex/gender is a – if not, **the** – major source of differentiation for human beings, and sex/gender (together) is a key determinant of health (Kaufert 1996; Love, Jackson et al. 1997; National Forum on Health 1997).

Chambliss has pointed out, “no one has the luxury of a gender-free view of the world, and there is plenty of evidence that the genders see the world differently” (Chambliss 1996, p. 80). This is the heart of the matter. A great deal of the research that has been done on health services and systems, including that focussed on health care reform, has ignored sex/gender, been silent on its significance as a determinant of health, or treats sex/gender as if it is less important than other characteristics such as socioeconomic status.

A recent report for the WHO Regional Office for Europe (Marmot and Wilkinson 1999; Wilkinson and Marmot 2000) illustrates just how severe the problem of gender-blindness is. In a text claiming to provide the “solid facts” regarding the social determinants of health, it is interesting to find minimal reference to sex and/or gender as determinants of health in their own right, or as related to other determinants of health. In the index, under the heading “women,” we are directed to “see females; mothers.” Under the heading “females,” the reader finds listings such as “customs,” “early life interventions,” and “nutrition.” Under the heading “mothers,” the reader finds listings such as “health during pregnancy”, and “separation from.” In short, women are viewed only in terms of their roles as

mothers. It is notable that the index contains no listing for “men,” “males” or “fathers.” One can only assume that the authors view men as normative, or that they do not consider that differences between women and men to merit consideration. Some reports on the determinants of health do recognize and investigate gender as a determinant of health (Acheson 1998; Health Canada 1999). The Acheson Report (U.K.) states that “Gender, like socioeconomic status, shapes individual opportunities and experiences across the life course. While many experiences of childhood are similar for boys and girls, they are exposed to different risks. Men and women occupy different positions in the labour market and in the home, which again bring different health risks” (p. 1). The Wilkinson and Marmot Report acknowledges that “social and economic factors at all levels in society affect individual decisions and health itself” (Wilkinson and Marmot 2000), yet the effects for women and men are ignored. Such omissions fly in the face of Wilkinson and Marmot’s claim to provide “the solid facts,” not to mention a considerable amount of evidence regarding gender as a determinant of health. Their gender-blindness reinforces Kaufert’s assertion that the determinants of health approach has left women out (Kaufert 1999).

Gender structures our opportunities in life, and influences our access to political and economic resources (Kaufert 1996). Reid observes that
 Research in the health inequalities field is often gender-blind and makes general statements about the shape of socioeconomic gradients in mortality and morbidity, or about causal processes, without examining whether these apply differentially to men and women (Macintyre and Hunt, 1997). When women have been added, observations on women are presented as additional results only, a procedure that has been characterized as ‘add-women-and-stir’ (Lahelma et al., 1999). (Reid 1999)

All of this is to say that it is important – actually, it is essential – that gender-based analyses be undertaken as part of the research on health care reform and its impacts. Such investigations are not only important to see the effects of health policy on women, but also on men since they, too, are gendered beings. As Eichler has pointed out, “Gender-based analysis of health research, policies, and programs will help to ensure that health practices are not gender-biased” (Eichler n.d.). The incorporation of measures of gender – as distinct from the biological variable sex – in studies of health and health care will also make it possible for us to more fully understand, and therefore develop strategies to improve, the

health of all Canadians, including the women of this country.

How the Narrow Range of Evidence in Health Care Research Misrepresents or Underestimates the Impact of Health Care Reform on Women

The lack of gender-based analyses means that it is difficult for us to assess how various health policies and practices affect women and men, how women and men have different (or similar) experiences of health and health care, and how different groups of women and men experience health and health care. A further difficulty arises because of how the impacts of health care reform are measured. The measures that are included and excluded in health surveys and public health databases clearly shape how we view what is going on in health care today. Values shape the questions we ask (and don't ask), the data we collect (and don't collect), and how we marshal that data as evidence. In turn, the nature of social change within the health care system, and in the larger society, are affected by the evidence presented.

The limited range of indicators used in studies of the health care system provide an incomplete picture, if not a misrepresentation, of the effects of health care reforms. This is true in general, and in particular when it comes to experiences in which there are known gender effects or differences. (It is probably useful to remember that it will be difficult to say much about gender effects if we don't ask the question or include appropriate measures.)

As previously noted, in an environment guided by evidence-based decision-making, the "best" evidence is usually defined as that which is "objective," quantifiable, and replicable. As a consequence, many studies of health care focus on data collected through quantitative methods. More often than not, "qualitative research is often relegated to supplementary roles in the generation of evaluation of evidence, such as planning or explaining quantitative research" (Rychetnik and Frommer 2000). John Ralston Saul, speaking at the 1998 Directions for Canadian Health Care Conference makes the following observation: If we are to have a meaningful debate about health care, however, we need to be exact in the way we identify and acknowledge the real nature of the current crisis. Allan Rock, the current federal health minister, may say that he is not interested in 'anecdotal evidence,' but Canadians themselves are feeling the system's pulse in the stories they live and witness every day. Health care is not an abstraction. Nothing can be more exact, more existential, than the experience of patients. These experiences tell us a lot about where our system is failing us. (Ralston Saul 1999, p. 7)

To repeat a comment made earlier, we need all kinds of data – utilization data as well as personal accounts that reveal what health care and the various reforms *mean* to people – to understand the exceedingly complex world of health care.

Across the country, researchers and research centres³ using population-based information systems (sometimes referred to as administrative data) have significant influence. Their conceptual approach, best reflected in the book *Why Are Some People Healthy and Others Not?* (Evans, Barer et al. 1994), has fundamentally altered public policy and institutions in this country (and perhaps around the world). The “population health” and determinants of health” approach is government policy in Canada at the federal level (Federal 1994; National Forum on Health 1997; Federal 1999; Health Canada 1999), and in the provinces and territories of this country. Initiatives such as the Canadian Institutes for Health Information (CIHI), and funding programs within the Canadian Health Services Research Foundation, and the now defunct National Health Research and Development Fund are all oriented around the question “why are some people healthy and others not?” The methodological approach advanced by those working in “population health” has also privileged certain kinds of research over others. In particular, population-based studies are viewed as the key to understanding what health care Canadians really need, and how best to allocate scarce resources in the health care system.

In Manitoba, for example, research conducted by the Manitoba Centre for Health Policy and Evaluation (MCHPE) has affected the provincial government’s policies regarding regionalization, restructuring, downsizing of hospital resources, and the coverage of selected health services (Praznik 1999). Policies in other jurisdictions have similarly been influenced by population-based studies conducted at other research centres. In short, there has been significant uptake of this type of

³In the last decade, the following research institutes have been established: The Centre for Health Evaluation and Outcome Sciences, The Centre for Health Services and Policy Research, and the Program in Population Health of the Canadian Institute for Advanced Research (all in British Columbia); The Health Services Utilization and Research Commission (in Saskatchewan); The Manitoba Centre for Health Policy and Evaluation; The Institute for Clinical Evaluative Sciences and The Institute for Work and Health (both in Ontario); Groupe de recherche interdisciplinaire en santé (Quebec); and The Population Health Research Unit (in Nova Scotia).

determinants of health research. But if the data upon which policy is being made is flawed or incomplete, we might rightly ask how good is the evidence upon which it is based.

Roos at the MCHPE describes the POPULIS database as an advanced data warehouse that includes administrative data collected by the Province of Manitoba, along with information on the characteristics of populations, vital statistics records, census data, and information on the supply of health services (Roos 1999; Roos and Shapiro 1999). There are many virtues of this type of data. Above all else, the data contained in such databases are already being collected, and there are the savings associated with not having to gather data anew. Such databases are also population-based, and therefore more comprehensive than studies of samples of the population. But are these databases sufficient? Do they tell us all that we need to know about health and health care, and in particular how private lives are affected by public policies?

At the MCHPE, the approach has been “to determine what is available and then to figure out how to use it” (Roos 1999, p. JS21). Roos says
 Waiting for the creation of new data sets that may contain more useful variables or more “validly constructed” indicators may make researchers more comfortable, but the timetables necessary for such projects are particularly unpromising. Our success has been not based on persuading administrators to collect more and better data... Our success has been based on finding data sets that meet the criteria [of our population-based approach] and working with these to identify how they might be used. (Roos 1999, p. JS21)

To be sure, this approach is a pragmatic one. But the danger is that imperfect data are being analysed and used to inform public policy.

To illustrate the limitations of the data, consider the February 1999 report by the MCHPE on hospital bed closures in Winnipeg. Brownell and Hamilton report that 727 beds were closed in Winnipeg hospitals in the period between 1992/93 and 1997/98, an amount totalling 24% (Brownell and Hamilton 1999). What were the effects of this hospital downsizing? Brownell and Hamilton report that hospitals cared for the same volume of patients with fewer beds by delivering care in different ways (e.g., by shifting care from inpatient to outpatient settings). As well, they report that the quality of care (measured rather crudely by hospital readmission rates) and the health of Winnipeggers (also measured rather crudely by premature mortality, that is, deaths before age 75) were unaffected by the bed closures. A

recently published report by researchers at the Centre for Health Services and Policy Research in British Columbia reached similar conclusions about the effects of hospital downsizing on elders' health care utilization and mortality rates (Sheps, Reid et al. 2000). These researchers conclude that there have been minimal adverse effects associated with the reduction in acute care services, that the reductions in acute care services coincide with public policy goals of (and citizen preferences for) shifting care "closer to home," and that longer term hospital stays are being reserved for those who are sicker. In an editorial regarding the Sheps et al. study, Roos contends that all of the headlines about hospital downsizing and bed closures exaggerate the effects of this type of health care reform. She confidently proclaims "Bed closures have not made it tougher for sick elderly patients to get into hospital. Claims to the contrary are false" (Roos 2000, p. 411). And in a somewhat dismissive remark, she says "if more people had bad experiences after bed closures than before, these results should be showing up in the 'data'" (Roos 2000, p. 411).

But what if the "data" are not designed to measure people's "bad experiences after bed closures"? What if, instead, the available measures simply reinforce an imperative dictated by the requirements of the system, an imperative which asserts that Canadians need to reduce their reliance on the health care system? If you don't measure the full range of consequences associated with health care reforms, how can you ever imagine that you will be able to ascertain what those effects are? The answers you get depend on the questions you ask. And as Ursula Franklin once remarked, "nonsense on a graph is still nonsense!"

Can the administrative data capture the effects of hospital downsizing, only one of many ways in which health care has been restructured and reformed in recent years? What are we to make of the other effects of bed closures, including the transfer of the responsibility for care to families (and to a large extent, to the *women* in families)? Is it sufficient to measure quality of care by indicators such as readmission rates (Benbassat and Taragin 2000)? Should we be looking at other dimensions of quality that reflect the psychosocial dimensions of care? Is it sufficient to rely on premature mortality rates when basic epidemiological principles suggest that mortality rates do not change dramatically in the short-run, but rather in the long-run? Are there not other indicators we ought to be employing to assess the effects

of such health care reforms on the population?

Research on the impact of health reforms, and in particular the shift of health care from institutions to the community and the home has not, for the most part, examined how lay providers (many of whom are women) are directly affected by policies such as early release from hospital and the shift toward outpatient care (Fast and Keating 2000). Similarly, it is not clear that we have sufficient information on the effects of health care reforms on professional nurses and paraprofessional workers in the health care system, the majority of whom are women (Leiter, Harvie et al. 1998; Manitoba Nurses Union 1998). What happens when closed beds mean fewer personnel, but the same volume of patients? What are the effects of work speed-ups, job consolidations, and various forms of de-skilling (Dickinson 1994)? How do these health care reforms affect the well-being of professional and home-based care providers? All of these questions must be answered before we can reach a definitive conclusion about the effects of bed closures. Without answers to these (and similar) questions, we cannot even begin to assess the effects of health care reforms such as hospital downsizing.

It is not only research using administrative data that suffers from inadequate measurement of key variables and gender blindness. In an otherwise comprehensive and helpful discussion paper for the Canadian Policy Research Networks entitled “Family Caregiving and Consequences for Carers: Toward a Policy Research Agenda,” Fast and Keating only rarely mention women who they do acknowledge continue to constitute the majority of carers (Fast and Keating 2000). This is especially ironic given their insistence that researchers must take particular care in defining key concepts such as “family,” “caregiving,” and “need.” By referring to “family caregiving” in a generic sense as if this is work done as much by women as by men (which it is not), and as if the work itself is the same for women and for men (i.e., the nature and meaning of the work, the internalization of a “duty to care,” the consequences of caring in terms of the carer’s ability to perform other social and economic roles and in terms of her/his own health, and the ability to obtain needed supports in that caring work) renders important differences invisible (Montgomery 1999). Fast and Keating are quite correct to recommend that research on health care and caregiving examine “the differential effects of policies” (Fast and Keating 2000). We also need researchers to use precise language – to say what they mean, and mean what they say.

There is a sizeable body of evidence that clearly indicates that caregiving is different when it is performed by women and by men, and as important, that the resources available to caregivers are different for women and men. Bernier and Dallaire (Bernier and Dallaire 1999, p. 35) state: if the caregiver is a man, the use of services is different. “[Translation] Male informal caregivers who are the main caregiver receive more assistance from other family members than do females who are the main caregiver (Walker, 1991). When a man takes care of his frail wife, he receives help from his daughters; such help is provided less when it is a woman caring for her husband (Roy et al., 1992). In the few cases where a son cares for his elderly parent, his wife – that is, the daughter-in-law – very often has a large amount of responsibility for the care. According to Mathews and Rosner (1998), a daughter who cannot or does not want to care for an elderly parent feels guilty and has to come up with good excuses. In the case of a son, not contributing to care seems normal (Vezina and Pelletier, 1998: 8).

Montgomery notes that “practitioners, who serve as gatekeepers for community resources, tend to offer greater supports to male caregivers and convey lower expectations for sons to provide direct care services” (Montgomery 1999, p. 392). There are suggestions in some of the literature – although there is little systematic empirical evidence – that male caregivers are better at accessing the system, and they get more help.

Several implications flow from these observations. First, we need to understand the nature of caregiving (including not only who provides the care, when and for how long, but also what services are accessed, what effects caregiving has on the provider, the recipient, and the systems of care). Second, we need better systems for tracking the experiences of caring for those working in and being paid by the system and those who supplement (or, in some cases, replace) the formal system. Third, we need to understand the various aspects and consequences of caregiving through a gender lens – that is, to identify how and why the experiences differ for women and men. Too few studies do this at present.

Little of this is captured in the “data” that is used to demonstrate the beneficial effects of health care reform. Administrative databases do not systematically record the effects of task consolidation, work speed-ups, and the redistribution of skills within the health care work force. Similarly, data to measure the effects on patients and their families are not included in administrative databases. This type of epidemiological (and health services) research reduces the various determinants of health to that which is “empirical” and “discrete.” Such criticisms are echoed in the work of Labonté, Blomley, and Coburn and

colleagues who have raised serious theoretical and methodological questions about the Canadian Institute of Advanced Research approach to the determinants of health (Blomley 1994; Labonté 1995; Coburn, Poland et al. 1996). Even Evans and Stoddart acknowledge that their approach which relies on quantifiable and measurable variables is one in which “precision is gained at a cost” (Evans and Stoddart 1990).

As noted previously, the point is not that we should ignore administrative data. Rather, we should see it for what it can and cannot tell us. Charles Dickens, an early and vocal critic of 18th British statisticians, decried “the dehumanization inherent in the process of aggregation” (Poovey 1994, p. 415). Today, we can recognize the value of population-based studies, and we can see that in addition to statistical representations of how the health care system works, we need additional information on how individuals, in their everyday round of life, experience and find meaning in their encounters with the health care system. This may not be discernable through measures of mortality, or even visits to physicians. Balint long ago established that medicine performs more than a technical function – it serves social functions as well (Balint 1957). If we want to study the health care system as if individuals mattered, we need to include them. And if we want to study the health care system as if women mattered, we need to include them as well. We also need to examine what the gender effects are for women and men so that the system is responsive to women’s and men’s needs.

Researching Health Care (Reform):
Toward an Integrative Approach

There are many ways of conducting research on health care reform and its impacts on individuals in society. All of those methods are needed to do justice to the complexity of the issues involved. In a paper written for the Interim Governing Council of the Canadian Institutes of Health Research, colleagues and I noted that:

1. Health is a multidimensional phenomenon that is far more than the absence of disease.
2. Individuals’ conceptions and experiences of health are situated within the contexts of their everyday lives.
3. It follows, therefore, that research on health must include the individuals’ standpoints about health if we are to capture that lived experience in meaningful ways.

4. There is no single approach that captures the nuanced experience of health and illness.
5. Wherever possible, complementary methods (quantitative and qualitative methods) should be employed to understand health. (Grant, Adelson et al. 1999, p. 5)

Daly and McDonald remind us that

different approaches to research will ask different questions, collect different data and use different frames of analysis. Indeed, methods of analysis can be based on varying philosophies of knowledge, and the criteria for judging what counts as rigorous within one method cannot be transferred to another with fundamentally different epistemological assumptions. It follows that, unless funding bodies are familiar with the full range of study designs applicable to health care, prejudice against certain methods will lead to a systematic neglect of important issues. Funding bodies which lack the necessary criteria for judging research using non-experimental methods of research run the risk of ignoring much-needed analysis of social and community issues in health care, and the necessary eclectic and interdisciplinary approach to research will be inhibited. (Daly and McDonald 1992, p. 5-6)

The issues in this area of public policy are extremely important and even urgent. For women, they are particularly pressing because heretofore our experiences have been hidden from view or perhaps taken for granted. Eichler suggests that “it may be necessary to rethink, and design new studies for women” (Eichler n.d.). Clearly, we need to use all forms of the data we have, and we need to work to develop better methods for studying health care reform and its impacts of all of us. For the sake of Canadian women and men, and for the sake of Medicare, we need to do this together.

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