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What counts and who's counted in women's health research?

WE NEED BOTH ADEQUATE CONCEPTS OF WOMEN'S HEALTH AND APPROPRIATE tools for measuring them in order to understand and evaluate interventions intended to benefit women. For example, women's health has traditionally been conceptualized in terms of reproductive issues. A more adequate conceptualization includes women's physical, mental, emotional and social well-being, and an understanding that health arises in a social world and physical environment that includes sex (biology), gender (social roles), work, race and culture—among other things—and the interactions among these factors. "New paradigms, methods, and measurement tools are urgently needed to expand the frontiers of women's health,"¹ says the Michigan Initiative for Women's Health, one of the many voices arguing for the development of new research tools and approaches to women's health research.

In this issue, two articles discuss aspects of what counts (and what is still missing) in measurements of women's health with respect to sex and gender. Colleen Reid suggests that traditional measures of women's and men's socioeconomic status, paid and unpaid work, and childrearing activities have lagged behind conceptualizations, particularly since the introduction of the determinants of health perspective. Reid argues that measurements must be revised to reflect the complexity and diversity of women's and men's lives today. In the second article, Shelly Abdool and Bilkis Vissandjée describe the features of a system of "gender-sensitive indicators" that would more adequately measure women's health. They offer criteria for the selection of these indicators.

Not only do we require new, appropriate measures, we also need to ensure that they reflect the diversity of the Canadian population. Catherine Frazee's article on the Canadian Biotechnology Strategy draws attention to the

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■ We need both adequate concepts of women's health and appropriate tools for measuring them in order to understand and evaluate interventions intended to benefit women.

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measurements that inform health research and policy making. She questions the notion of the “ideal citizen” that underpins the Strategy, suggesting it implicitly excludes people with disabilities. In contrast, another article describes the work of Connie Deiter and Linda Otway who use specific research methods to include the participation of Aboriginal women, an often-neglected group. Researchers Anne Fenety, Carol Putnam and Charlotte Loppie describe the methodological challenges of including a new group of women workers in an occupational health study. In new, non-unionized and rapidly growing industries such as call centres, partnerships between industry and health researchers, which could facilitate the participation of workers, are largely untried.

In thinking about how to advance sex- and gender-sensitive research, we note that the British Columbia Centre of Excellence for Women's Health has released “Fusion,” a model for integrated health research. Developed in consultation with members of the women's health community, the “Fusion” approach helps to assure relevance and inclusivity, encourage multidisciplinary, integrate sex and gender, share paradigms and foster policy relevance.

In an article that advocates for the continuing need for gender-based analysis to assess the effects of health policies and programs on women and men, Karen Grant diagnoses

the current situation as afflicted with “The Red Queen Syndrome.” Like Alice in *Alice in Wonderland*—running as fast as she can to stay in the same place—women's health researchers face a prevailing resistance to the inclusion of gender in health research.

Several of these authors argue that *most* of health research today is “gender neutral” and ignores the possibility of differences in the health of women and men. The evidence is mounting that such research is not at all “gender neutral” in terms of its effects. This issue of the *Research Bulletin* challenges health researchers and policy makers to make sure that what, how, and who we count in research reflect a comprehensive understanding of the many factors that influence health and illness, and the many people we may exclude or include depending upon the methods and concepts we choose.

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WHAT COUNTS IN HEALTH RESEARCH?

A Full Measure: Women's Occupational Status and Health

Colleen Reid, British Columbia Centre of Excellence for Women's Health

Currently, the determinants of health perspective conceptualizes women's health as a complex mix of social, political, economic and biological factors. Yet measurements of women's health have typically relied on a biomedical model, viewing health as independent from the social environment. This gap between the conceptualization of the determinants of health and measurements of health affects research, policy and practice. A new study called *A Full Measure* discusses this gap between conceptualizations and measurements of women's health and suggests ways to advance measurements.

When applied to women's health, standard measurements often result in oversights, errors, inconsistencies and simplifications. Oversights occur when crucial daily experiences of women's lives are not considered and when women are excluded from health studies, inconsistencies in research results occur when inappropriate measurements are applied or compared, and stereotypical assumptions about women's and men's roles lead to simplifications of complex issues.

A literature review and analysis, *A Full Measure* considers conceptualizations and measurements in three areas: the biological, socioeconomic and sociocultural dimensions of women's health. In the chapter on biological dimensions of women's health, problems with morbidity data are examined. One problem is that these data do not indicate highly significant events in women's lives, such as rape, or low-level problems, such as arthritis or problems with

childcare.¹ The chapter on sociocultural dimensions explores the discrepancies between understandings of women's diversity (which encompass, for example, class, race/ethnicity, immigrant status, sexual orientation, age/lifespan, geographical location and ability/disability) and measures of women's diversity, which consider only race/ethnicity and age.

For the purposes of this article, one measurement in the socioeconomic dimension of women's health—occupational classifications—is discussed.

Occupational Classifications

Socioeconomic status typically refers to an individual's occupation, education, personal income, family income, or low-income geographic area. A significant barrier to understanding the link between women's socioeconomic status and health is the way in which occupation is measured. Because women are less likely to have paid work and tend to occupy different jobs than men, standard occupational classification systems that were developed to reflect men's work are inappropriate for understanding the relationship between women's work and health.²

i) Gender segregation in work

When women are employed they are concentrated within a limited number of occupations that tend to have relatively low wages and status. Given this entrenched gender segregation, measures based on occupations inevitably raise

Few studies have attempted to treat work and home conditions symmetrically, although those that do have found that work conditions may be just as or more important for women's health as for men's.

problems. When comparing occupational income inequalities in men and women, for example, it becomes clear that women in “male” occupations will generally remain in the least senior positions and earn less money, while men in “female” jobs are over-represented in more senior positions. This means that women are over-represented in low-paying, low-status and low-security jobs and have a different experience and relationship to the paid labour force. The “Registrar General’s Classification” in the United Kingdom was constructed based primarily on male occupational and work experience. It remains an example of one such problematical measure that is still widely used.³

ii) Biases in assumptions about the impact of work

There has been some suggestion in health research that work-related factors make a greater contribution to men’s health status and that family situation and family composition factors may be more important for women’s health.⁴ This assumption prevents us from fully understanding gender differences in the relationship between socioeconomic status and health. Women’s paid work has been treated as an additional rather than a primary role: this belies an unstated, stereotyped assumption of a traditional unpaid role for women as homemakers. Few studies have attempted to treat work and home conditions symmetrically, although those that do have found that work conditions may be just as or more important for women’s health as for men’s.⁵

Women and men occupy particular sections of the labour market, though this has not been well measured or reflected in measures of work and occupation. This means that gender differences that have been found in the relationship between health and socioeconomic status may in fact indicate problems in the measurement of social status and paid work. Given that women tend to occupy particular sections of the labour market, the magnitude of socioeconomic inequalities between women and men might reflect gender differences in the measurement of social status, rather than true differences in the relationship between health and socioeconomic status for men and women.

A telling contradiction in health research is that men who are unemployed (unpaid) are seen as experiencing a disadvantage. With few exceptions, studies of men’s health have paid less attention to their marital and parental roles.⁶ Arber and other feminist researchers have stressed the

importance of examining both women’s and men’s occupational position within society and the family. Socioeconomic indices, such as education, should be considered as another means to measure socioeconomic inequalities between women and men. Measuring education can “round out” or provide a more complete representation. This has been applied in studies on men’s health where there is greater inequality between men.⁷ Using similar socioeconomic indicators for comparisons of men and women rather than examining different sorts of indicators for each sex⁸ could produce more accurate understandings.

iii) Primary and additional roles

The demands of housework and childcare are additional stresses for women who are also paid workers. For this reason women’s employment should be examined as both a primary and an additional role. As a primary role, paid labour influences a woman’s command over financial resources and may influence her and her family’s lifestyle and life chances.⁹ Women’s parental and marital roles within a particular setting are also significant, but little research has been done to examine the link between health and these roles.¹⁰ Traditional measures also neglect the experience of lone female parents.¹¹

iv) Unemployment

Some research has shown that unemployment causes poor mental and physical health. Other research on men supports the notion that it is those who are already less healthy who are selected into unemployment. Research on women’s health and paid employment complicates this debate. This research has focused on whether or not paid employment improves or inhibits women’s health. Contradictory findings have resulted: some researchers contend a “healthy worker effect,” that paid work improves women’s health, while others believe that combining paid and unpaid work results in undue burdens of responsibility and “role accumulation” and can negatively impact women’s health.¹²

Implications for Research on Socioeconomic Status and Health

The development of appropriate tools to measure women’s health has lagged behind conceptualizations of social and structural influences. Traditional measures of women’s and men’s socioeconomic status, paid and unpaid work, and childrearing must be reviewed and revised to accurately reflect the complexity and diversity of women’s and men’s lives. As women’s and men’s relations to the formal labour

market and to the domestic sphere change, it is particularly timely to examine the meanings and measurements of work and class for both sexes. This research could illuminate similarities and differences that may provide clues to the causes and origins of various social inequalities in health.¹³

For a copy of the full report, *A Full Measure: Towards a Comprehensive Model for the Measurement of Women's Health* (2001), contact:



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WHAT COUNTS IN HEALTH RESEARCH?

Towards Gender-sensitive Health Indicators

Shelly N. Abdool, Bilkis Vissandjée, Marie Desmeules, Jennifer Payne, Centre d'excellence pour la santé des femmes–Consortium Université de Montréal¹ and Centre for Chronic Disease Prevention and Control, Population and Public Health Branch, Health Canada²

A new inventory provides summary tables of women's health indicators compiled from Canadian and international databases. The inventory also describes features of gender-sensitive indicators that could, if applied, provide a more adequate system of health surveillance for Canadian women. Indicators are important instruments in the measurement and evaluation of women's health and are defined as "a flag, marker or sign that points to a condition you want to measure."³ An indicator can be a number, a fact, an opinion

or a perception about a specific condition or situation.⁴

To construct the inventory, we reviewed databases of academic literature and documents from research groups and government dated from 1995-2000. All documents were critically reviewed for indicators of health/women's health, conceptual frameworks and determinants of health that apply to women's health. "Classic" documents, such as the Lalonde Report⁵, were consulted regardless of release date, as

■ Although indicators arise from a wide range of conceptual frameworks, gender and culture have the least number of indicators with respect to health.

were articles prior to 1995 when they were cited by more than five references.

Our inventory is organized into four large indicator domains: the determinants of health, basic population characteristics, health status and health consequences. (By *determinant*, we mean the genetic, social, economic, lifestyle and environmental factors that are influential independently or in combination with one another. These are drawn from Health Canada's *Women's Health Strategy*.)⁶

By evaluating the quality and limits of indicators and determinants and the data resulting from their use in specific literature, the inventory exposes neglected areas. Significantly, although indicators arise from a wide range of conceptual frameworks, gender and culture have the least number of indicators with respect to health. Also, although one in six Canadians is an immigrant,⁷ the migration experience is not currently considered as a determinant of health. It is important that any indicator used to measure the health of women includes features that consider individuality, diversity, and differences from men, especially in the context of migration.

Sex and Gender

At their foundation, all indicators should entail gender analysis⁸ and have a solid comprehension of the difference between *sex* (biological distinctions between women and men)⁹ and *gender* (socially attributed identity constructed by relations of power that dictate the choices and chances available to women and men, girls and boys).¹⁰ In order to move beyond explanations of women's health that reduce women to their reproductive capacities, the study of *gender relations* is also crucial. Gender relations refers to the often, but not always, asymmetrical relations of power based on sex differences that are crucial in accounting for gender differences in health.

Gender-sensitive Indicators

Gender-sensitive indicators measure gender-related changes in society over time. These indicators should provide evidence of

the status of women relative to some agreed normative standard or explicit reference group (e.g., relative to men of the same population or to women in other communities or countries).¹¹ For example, a gender-sensitive indicator of social empowerment would be defined as one that measures the desired autonomy of women/men over fertility decisions (e.g., number of children, number of abortions, etc.).¹² Also, both quantitative and qualitative methods are needed for women's health because they are complementary, equally effective for monitoring and evaluation, and because they can cross-validate and highlight each other's shortcomings.

For all health indicators, there must be consensus as to what degree of imperfection will be allowed in their definition. This is generally regulated by testing to make sure that the indicator is valid (measures what it is supposed to measure), and reliable (measures in a consistent manner), but these must be conceived from a gender perspective to assure the quality of an indicator for women's health.

Selecting Gender-sensitive Indicators

The following criteria are suggested as important markers in national level gender-sensitive indicators or indicator systems:¹³

1. Comparison to a norm: For example, the situation of men in the same country or that of women in another country, in order to focus on questions of gender equality and equity rather than on the status of women, a term which tends to have definitional discrepancies.
2. Disaggregation of data by sex. Where possible, data should also be disaggregated by age, socioeconomic status, country of origin (or birth country, including the length of time spent in said country), geographical coverage (e.g., Canadian indicators should include data from all provinces and territories, including isolated areas and Native Reserves, in order to have an appropriate geographical coverage and attend to disparities), as well as ethnic and racial group.

3. Scope of availability: Indicators should not only be reflective of the entire country but also be available for the entire country.
4. Reliability: The extent that data can be free of bias or error (e.g., reporting errors, issues of recall when asking people to re-visit childhood or traumatic experiences, tendency to under-report alcohol or tobacco consumption, etc.). The user should know how the indicators were constructed.
5. Measurability: For less precise concepts, such as women's empowerment, proxy indicators should be used (e.g., greater choice for women in accessing health care).
6. Where composite indices are devised, value assumptions of selection and weighting must be made explicit.
7. Time frames: Gender-sensitive indicators should be reliable enough to use as a time series and the time span of indicators should be stated clearly.
8. International comparability: Indicators should be collected using internationally accepted definitions in order to allow for international comparison.
9. Participation: Indicators should be used and developed in a participatory process with stakeholders. It is important

that women themselves are involved in identifying health needs and priorities and their relevant indicators.

This inventory contributed to discussions held by the Population and Public Health Branch of Health Canada on indicators to include in a Surveillance Report Card on Canadian Women's Health.

For a copy of *An Inventory of Conceptual Frameworks and Women's Health Indicators* (2001) contact:



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WHO'S COUNTED IN HEALTH RESEARCH?

Silent Measures: Disability and the Canadian Biotechnology Strategy

Catherine Frazee, former Chief Commissioner of the Ontario Human Rights Commission (1989–1992), Instructor, Disability Studies Program, Ryerson University, and Research Associate, Roeher Institute

A version of this paper was first presented at The Canadian Biotechnology Strategy: Assessing Its Effects on Women and Health – a National Strategic Workshop held at York University in February 2000. The workshop proceedings, The Gender of Genetic Futures, appear in the Working Paper Series of the National Network on Environments and Women's Health.

The internet site for the Canadian Biotechnology Strategy (CBS) welcomes me with the Canadian flag, the Industry Canada banner and the greeting, “The Information Site That Means Business!”¹ This is not a site for casual browsers. But I do have business here—I am a stakeholder. And I have come seeking purchase.

I am a disabled woman. Reading through the web pages, I feel something slipping away, something integral. I scour the site—the press releases, fact sheets, background papers, consultation documents and committee reports. My browser's “Find” command storms through each document in pursuit of a single fugitive word. But “disability” appears nowhere. It is alluded to, in phrases like “recognizable problems attributed to chromosomal, monogenic or multifactorial mutations” or “genetic deficiency.”² It is implied, surely, in the promise that “Genetic testing will provide a number of diagnostic benefits such as the potential for...helping potential parents make informed decisions.”³ But the shadowy foe never quite declares itself.

The Strategy promises “to enhance the quality of life of Canadians in terms of health, safety, the environment, and social and economic development.”⁴ But what does this mean? To answer I will investigate four phrases from CBS documents. Each states a noble purpose, yet there is an equivocal quality to each when viewed through a disability lens.

“Biotechnology as a Key Contributor to Quality of Life”⁵

How does biotechnology contribute to quality of life? It would appear that the Strategy intends this to derive, in part, through the prevention of genetic disease or defect. This presumes first, an identifiable genetic “norm,” and second, some social consensus that the “norm” is inherently more desirable than the “deviant” form.

Implicit in the identification of “genetic disease” (e.g., as applied to conditions such as Down syndrome, Spina Bifida and Muscular Dystrophy) is the assertion that disability is a negative characteristic—“*a priori* an undesirable trait.”⁶ I would be the first to concur that disability—like gender and race—correlates strongly with disadvantage. But while it is widely recognized that the disadvantage experienced by women and racial minorities is directly attributable to the social and systemic evils of sexism and racism, the non-disabled majority seems to stumble again and again in applying a similar analysis to the human rights claims of persons with disabilities. Instead, majoritarian thinking uncritically situates disability disadvantage as intrinsic to individual impairment or nonconformance to physiological and intellectual norms.

Biotechnology's vigorous focus on disability prevention by genetic methods ignores the deeply embedded and pervasive social, economic and political determinants of disability disadvantage. Disability activists and theorists have emphatically asserted that disability is located in social and economic structures, and that it correlates most strongly with access to money, supportive personal relationships and control over living conditions. How can we “popularize” this inherently unpopular notion?

Of course I cannot deny that living with a non-typical body can and often does add to life a significant dimension of pain, loss and restriction. But as I have argued at length in other forums, the same can surely be said of other states generally accepted as socially desirable—for example, growing up, entry into intimate relationships and parenting. The point is, as Adrienne Asch noted in her recent debate with Princeton ethicist Peter Singer, “disability is only one characteristic of any person's life. Along with disability—whatever that disability happens to be—come a whole range

■ My browser's "Find" command storms through each document on the Canadian Biotechnology web site in pursuit of a single fugitive word. But "disability" appears nowhere. The shadowy foe never quite declares itself.

of other characteristics...and redeeming benefits...both intrinsic and extrinsic."⁷

Disability per se cannot be presumed to diminish quality of life. Unless, of course, we are talking about the quality of life (read privilege) enjoyed by non-disabled Canadian citizens. Perhaps encoded in the phrase "quality of life" are forecasts about our national standard of living, and embedded in these, concern for allocation issues arising from escalating costs in health care and health support. This may well be so, but if it is, it must be made explicit. How else can those of us with genetically non-typical bodies find solid footing from which to enter into allocation negotiations?

"Helping Potential Parents Make Informed Decisions"⁸

For persons with non-typical genetic characteristics deemed undesirable by a non-disabled majority, the very possibility of entry into the human family becomes contingent upon a prospective parent's capacity to resist institutional pressure, reject social stereotypes and withstand the inevitable censure of peers and relations.

Most women over 35 elect to have prenatal diagnosis, and if they are told that their infant will have a "major defect" most of them decide to abort. As Peter Singer explains tersely, "If, before life has begun, the prospects are clouded, better to consider starting again."⁹

But what criteria or standards define an "informed decision"? For those of us with "undesirable" genetic characteristics that could have been detected before birth, the implications of such informed decision-making are genocidal.

The genetic structure of the fetus is such a small piece of the story of who we are and who we will become. The gifts and contributions of personhood will forever elude the predictive capacity of biotechnology. It is Singer's argument that some information is better than no information when decisions must be made in conditions of uncertainty. But surely a shred of information—nothing more than a dim flicker, enough only to render the purity of darkness into a labyrinth of shadowy distortions—surely this does not transform a leap of faith into an informed decision. As Natalie Angier asks, "Does that power [over the outcomes of reproduction] give us greater freedom, or does it deprive us of one of life's most unsung freedoms: the freedom to have things happen on their own?"¹⁰

"Reflecting Canadian Values"¹¹

Are the courts, the universities or the media our arbiters of cornerstone Canadian values? History teaches us that determinations of human worth are always consistent with the qualities that decision-makers have presumed themselves to possess—"the sort that facilitated passage through schools, universities and professional training."¹² As we develop "increasingly sophisticated means to detect—and potentially to prevent—difference in genetic structure, [we find ourselves living in] a time when our public policies reflect an increasingly inhospitable climate for difference. More and more, the Ideal Citizen is seen as the individual who demonstrates self-reliance, efficiency and competitiveness."¹³

The values and aesthetic preferences that prevail in our society will determine biotechnology's agenda and presumptions. They will influence not only how questions are answered; more than this, they are the breath with which

every question does or does not find utterance. One of the questions I am asking is how can we reinvent the Ideal Citizen as one with the capacity to form deep relationship, to give or experience joy, to create, to open new pathways for expression of personhood?

“Biotechnology for Public Health Advantage”¹⁴

Contrary to the expectations and preconceptions of non-disabled Canadians, many people with genetically non-typical bodies enjoy the quiet and priceless joy of medically uneventful living. How can those of us with genetically non-typical bodies reconcile CBS's notions of health promotion with our own identity and experience as *healthy* women?

School-aged children who are shown pictures of a wide range of “potential friends” and asked to pick the ones with whom they would be most likely to become friends, choose children who look like themselves and reject children who look different. Obese children, children with disabilities, children of different racial groups are eliminated quickly, for reasons the children making the selection find difficult to articulate. Regrettably, adult architects and engineers of public policy commonly demonstrate the same aesthetic

preferences in definitions of health, similarly unconscious and silent. The tyranny of designer culture accounts for much of my unease with the CBS and its squeamish reluctance to taint the pretty vistas of our genetically rich future with the nasty business of disability.

For the full paper, *Obscuring Disability* (edited by Fiona Miller, Lorna Weir, Roxanne Mykitiuk, Patricia Lee, Sue Shewin) see “The Gender of Genetic Futures” at www.yorku.ca/nnewh.



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WHO'S COUNTED IN HEALTH RESEARCH?

The Challenges of Studying the Health of Women Working in Call Centres

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Call centres are a relatively recent phenomenon in the work environment. In the Atlantic region, this rapidly expanding industry employs thousands of women. Call centre teleoperators use telephones and computers and either make calls for telemarketing, fundraising or conducting surveys, or receive calls, providing service via 1-800 numbers. Scripted dialogue, shift work, electronic performance monitoring of telephone conversations and a high degree of verbal interaction with the public characterize this occupation.

With few exceptions,¹ research has not considered the impact of this type of work on the health of workers. What is known indicates that tele-operators are susceptible to repetitive strain injuries of the upper extremities.² Attributable to physical ergonomic factors (e.g., environment, furniture, etc.), these injuries are also associated with work organization and psychosocial factors such as work/rest schedules, fear of job loss, low control over the work and a lack of co-worker and/or supervisor support.³

Given the limited knowledge in this area we wanted to use qualitative research techniques as a first step to identify the impact of job stressors and job modifiers. We wanted to accomplish this by talking to women who work in call centres in New Brunswick and Nova Scotia. *Job stressors* include physical, psychosocial and work organization stressors. *Job modifiers* include non-work factors such as family demands and the age of the individual. In the short-term, job stressors may lead to acute reactions that are psychological (e.g., job dissatisfaction), physiological (e.g., neck discomfort) or behavioural (e.g., absenteeism). In the long term, if unchecked, these acute reactions may manifest as illnesses or injury.⁴

The primary goal of our study, *Who's on the Line?* (2000), was to facilitate collaboration and expand partnerships between representatives from the call centre industry, government, unions and arms-length government organizations such as the Women's Employment Outreach Program and the Nova Scotia Advisory Council on the

Status of Women. We wanted to develop these partnerships in order to create effective evaluation tools and disseminate research about the impact of work experiences on the health of female call centre operators.

This article describes the difficulties we encountered in developing partnerships with industry, which in turn led to difficulties in recruitment of participants and necessitated changes to our research methods. These difficulties—which were overcome to a significant degree—reflect the unique challenges of conducting work-based health research in a new, rapidly growing and primarily non-unionized industry.

Recruitment of Study Participants

We contacted a number of call centres and invited them to partner with us in the research. Although representatives of middle management at two call centres expressed an interest in the project, when our proposal was presented to upper management the invitation to participate was declined.

In the process of trying to develop these industry partnerships, we were able to tour two local call centres and meet anonymously with a few individuals from personnel and occupational health departments who provided us with details that helped to inform the research process as well as the development of our interview guide.

Our initial intent was to conduct focus group discussions as the primary method of data collection for the study. The lack of support from upper management made industry-based recruitment impossible. Further, we anticipated that the relative openness of focus groups might inhibit people from addressing the more stressful aspects of their job if the focus group were composed of individuals from the same work environment. We opted to use individual interviews instead.

We found the task of recruiting study participants on an individual basis more complex, time-consuming and expensive than industry-based recruitment. As a result, the inclusion of participants from New Brunswick was not possible. Even

though recruitment was restricted to Nova Scotia workers, a wide variety of call centre types was represented based on business type, size and operational hours.

The partners we were successful in inviting into the research enterprise were the Women's Employment Outreach Program (WEO) in Halifax and the Atlantic Communications and Technical Worker's Union (AC&TWU). The latter affiliation served our research objective of informing unions about the unique issues faced by call centre workers. Representatives from WEO and AC&TWU helped recruit some study participants. Most were recruited via advertisements placed in local newspapers and through an inter-campus electronic notice board.

A total of 25 women, ranging in age from 20 to 58, were interviewed. A slight majority of participants (56%) worked part-time hours, 44% full-time. As well, 65% of the women worked variable shifts; the rest had fixed work schedules.

Research Findings

Although the relatively small sample size limits generalizations of our research findings beyond the tele-operators who participated in the study, (a result of the difficulties of establishing partnerships with industry), the interviews with the women yielded a breadth of descriptive information. New and critical data about the health and well-being of these female tele-operators were uncovered.

While some workers found their work fulfilling, others found it quite stressful. This range appears to be a result of different management styles and different types of call centres, both of which contributed to varying levels of perceived control on the job. Lack of control was related to: scripted dialogues, heavy workloads, excessive supervision

and surveillance of calls, job insecurity, interference with family responsibilities, and unpredictable work schedules (including rotating shifts and uncertainty of holidays). The collective effect of various job stressors including lack of control, negatively impacted the well-being of our study participants through varying degrees of low energy, depression, irritability, disrupted sleeping and eating patterns as well as poor overall mood.

The findings of this research indicate the need for future exploration of the psychosocial factors impacting the health of call centre workers. Our research results, as well as subsequent analysis of the entire data set, will inform the development of a call centre-specific occupational stress questionnaire. A brochure outlining our research results to potential call centre employees is being distributed through the WEO and other employment assistance programs. Despite the difficulties encountered in developing industry partnerships, we consider this a critical component of workplace health research. Our research initiatives continue to include this partnership strategy.

For a copy of the full report, *Who's on the Line? Women in Call Centres Talk about Their Work and Its Impact on Their Health and Well-being*, contact:



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WHO'S COUNTED IN HEALTH RESEARCH?

Research as a Spiritual Contract: An Aboriginal Women's Health Project

This article is based on an interview with Connie Deiter, Researcher, Prairie Women's Health Centre of Excellence.

Connie Deiter is co-author with Linda Otway of Sharing Our Stories on Promoting Health and Community Healing: An Aboriginal Women's Health Project.

In the past, when an anthropologist approached a First Nations tribe to document, for example, a ceremony, it would sometimes happen that faulty information would be given.¹ If the researcher failed to “pay” for the knowledge being offered, he risked putting himself and the giver of that knowledge in jeopardy. In Cree, *pastahow* refers to this spiritual harm or “debt” that can be visited upon the relatives or future generations of the giver or receiver of knowledge if proper payment is not made. If you take something from someone, you have to give something back: this keeps life in balance. In this way, all knowledge is spiritual knowledge.

Connie Deiter and Linda Otway, two researchers affiliated with the Prairie Women's Health Centre of Excellence, recently completed a study in which they put this principle into practice. “When Linda Otway and I approached First Nations women elders for our research on health and community healing,” says Connie Deiter, “we brought them traditional gifts of pouch tobacco and cotton broadcloth, and an honorarium. In a way we were following a ‘research method’ we’d been taught as children. When we asked an elder to teach us something or pray for us, we paid them with a gift. The skill or benefit we gained would, in turn, accrue value to our family and community. When we asked for knowledge to be shared in our research study, we knew we were entering into a spiritual contract.”

The completed study, *Sharing Our Stories on Promoting Health and Community Healing: An Aboriginal Women's Health Project*, indicates that definitions of health, healing and healthy communities, as articulated by the women Otway and Deiter interviewed and those who answered their survey, still carry remnants of these old teachings. “An enduring concern about ‘balance’ and *pastahow* is apparent,” says Deiter. “What you do now, or is done to you, puts in place what will happen in the future; how we treat each other has a fundamental impact on our health. Although elders expressed these views in explicitly spiritual terms and the (mostly younger) women in the survey in primarily secular terms, most of the women's responses indicate a broader understanding of health than is offered by a biomedical view alone.”

A total of 98 women from Manitoba and Saskatchewan participated in the study, including five elders. “Because so much of First Nations history has not been recorded, we wanted to talk to older women who had experienced residential schools. Women who knew the old permit system, which required people to get a pass from an Indian Agent to receive medical care. With the elders,” Deiter says, “we used an interview method that allows for an oral history to be given if the speaker wishes. We asked one question only, ‘What do you think ‘health’ is?’ The elders’ responses

■ If you take something from someone, you have to give something back: this keeps life in balance. In this way, all knowledge is spiritual knowledge.

commonly placed 'healing' and 'health' within both personal and historical contexts, linking colonization and illness."

Amy, a Sioux grandmother from Oak Lake, Manitoba, who is diabetic, said, "My health problems, I believe, began when I was eight years old. Now I'm sixty-seven. In between there I went through a lot of mental, physical, sexual [abuse]. When I was taken out of my home and taken to a residential school—from that first day, that's when my illness started. Through healing I went back to ... my Indian and Dakota way. Since I sobered up twenty years ago, the Creator has helped me and I help others." Inez, a Plains Cree elder in her late sixties, recalls, "For a long time at Onion Lake residential school, I had what was called a 'running ear'; nothing was done.... Today, I follow the Indian way. I always go back to my reserve for healing and rest."

The top health concerns identified by the elders were family violence, diabetes, and the need for better coverage of non-insured medical expenses. Although prescription drugs are "free" to First Nations people under the Indian Act, Deiter points out that a number of the women said that they were usually only covered for "older" drugs. "If they wish to have the newer (and more effective) drugs, they have to pay for them themselves."

Although the majority of survey respondents were younger women, 70% concurred with the elders in identifying family violence as their number one health concern. They chose this over options including Fetal Alcohol Syndrome, hypertension, and cancer. Again, like the elders, they listed diabetes as a second priority, followed by substance abuse and mental health issues.

Most respondents said their communities were not healthy and their definitions of "healthy" showed a high degree of consensus. A common description was, "[a place] where everyone works together and watches out for one another." One woman wrote that a healthy

community is "one that is free of ill-health [or] comprised of people who, despite ill-health, are intellectually, spiritually ... and emotionally sound."

Confirming other research about the poverty of Aboriginal women in Canada,² the data showed that 57% of the respondents live on incomes of less than \$20,000 a year, only 40% are employed full or part-time, and 35% are single parents. Although some identified "good food" as part of good health and most of the women said their nutritional requirements were being met, some qualified this by stating that they regularly could not afford to buy fresh foods. "Can't afford the Canada Food Guide" was the cryptic comment of one woman. "Of the 28% who said their nutritional requirements were not being met," Deiter points out, "some stated that they have gone without food to ensure their children were fed."

"Our study reveals that Aboriginal women see health as a holistic condition, largely created by the community and for the community," Deiter says. "We used a variety of research tools to find this out, but it was essential, in our view, to include methods that were appropriate to the culture we were studying. And now it's essential for governments to embrace this view of health and empower Aboriginal women to realize it."

For a full copy of the report *Sharing Our Stories on Promoting Health and Community Healing: An Aboriginal Women's Health Project* (Project #31) contact:



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Gender-based Analysis: Beyond the Red Queen Syndrome

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This paper was prepared for the Gender-based Analysis Fair, January 2002, Ottawa.

The call for gender-based analysis (GBA) is not a new one. The Canadian International Development Agency pioneered the concept of GBA in the mid-1970s.¹ In 1995, the government of Canada adopted a policy requiring federal departments and agencies to use GBA to inform policies and legislation. Although some in government have been applying the techniques of GBA for a long time, this equity-seeking strategy has been met with resistance in some quarters, and outright hostility in others.

Early on, advocates saw GBA as a strategy to identify sources and consequences of inequalities between women and men. Since many of those inequalities still remain, the need for GBA continues, but putting such arguments forward is not always welcome. We still need GBA to determine whether programs, policies and laws work for equity, and, it follows, whether these programs, policies and laws work for women.

In the context of the backlash against feminism, it seems that what has been taking place in recent years is akin to Alice's encounter with the Red Queen in *Alice Through the Looking Glass*:

Alice never could quite make out, in thinking it over afterwards, how it was that they began: all she remembers is, that they were running hand in hand, and the Queen went so fast that it was all she could do to keep up with her: and still the Queen kept crying 'Faster! Faster!', but Alice felt she could not go faster, though she had no breath left to say so. The most curious part of the thing was, that the trees and the other things round them never changed their places at all: however fast they went, they never seemed to pass anything. . . just as Alice was getting quite exhausted, they stopped, and she found herself sitting on the ground, breathless and giddy. The Queen propped her up against a tree, and said kindly, 'You may rest a little, now.' Alice looked round her in great surprise. 'Why, I do believe we've been under this tree the whole time! Everything's just as it was!' 'Of course it is,' said the Queen. 'What would you have it?' 'Well, in our country,' said Alice, still panting a little, 'you'd generally get to

somewhere else – if you ran very fast for a long time as we've been doing.' 'A slow sort of country!' said the Queen. 'Now, here, you see. It takes all the running you can do, to keep in the same place.'²

This running faster and faster to stay in the same place—the Red Queen syndrome—seems to define equity work. We should move beyond this, if we can. What are the obstacles to doing so?

First, it is not apparent that GBA or gender mainstreaming occurs in a systematic way right now. Indeed, Wendy Williams suggests that despite embracing GBA as a policy tool at the federal level and in some provinces, most policies have been developed without serious consideration of how women and men will be affected.³ Second, too often it is assumed that GBA addresses women's issues only. The whole point of GBA is to identify if and how programs and policies affect women and men similarly or differently—it is a question to be answered.

Let me make my point through some examples. If we look at the area of health and health care, the need for a gender lens could not be clearer. Decades of research in the social sciences confirms that sex is one of the most fundamental sources of differentiation among human beings.⁴ There are volumes of research that demonstrate the importance of sex as a determinant of health status.⁵ For example, studies show that women have a higher blood alcohol content than men even when they consume the same amount of alcohol. This is true even when one holds body size constant. As well, research indicates that women are significantly more likely to develop lung cancer than their male counterparts who smoke the same amount of tobacco.⁶ Drugs often produce different effects in men and women.⁷ Findings such as these have led the Society for Women's Health Research to advocate an approach they call "gender based biology," that is, scientific research dedicated to identifying "the biological and physiological differences between men and women."⁸

As important as sex differences are (e.g., differences at the physiological, biochemical or genetic levels), social scientists

have shown that there are also significant differences based on gender. That is, the different roles, responsibilities and activities prescribed for women and men, based on cultural conventions and expectations. These differences relate primarily to power—the relative possession or absence of it. Gender differences are evident in most areas of everyday life, hence the need to consider how programs, policies and laws affect women and men. Gender differences are evident in health behaviours, health care work and doctor-patient interactions, and are an enduring phenomenon in this society, and around the world. The importance of these differences has been recognized by federal/provincial/territorial ministers of health, and was highlighted in the *Women's Health Strategy* of Health Canada, which identifies gender as one of the determinants of health.⁹ To illustrate, consider the following key gender differences that make a difference in women's health:

- Women are much more likely to engage in health protective behaviours, including health screening (e.g., breast self-examination, regular check-ups).¹⁰
- Women are the fastest growing risk group for HIV/AIDS, yet HIV/AIDS is mostly an invisible epidemic among women.¹¹ The primary routes of transmission for women are heterosexual activity (64% of cases) and intravenous drug use (11% of cases).¹² Gender factors, such as women's ability to negotiate safe sex practices, may influence women's risk of the disease.¹³ The efficacy of treatments may be affected by both sex (e.g., drug metabolism) and gender (e.g., lifestyles).¹⁴
- Women and men do not receive the same (or similar) care, even for the same conditions.¹⁵ American studies show women are less likely to receive high-tech services, and tend to receive less aggressive care for conditions such as heart disease and cancer.¹⁶
- According to the National Population Health Survey, stress levels among women have been on the rise between 1985 and 1991. The rates in Nova Scotia show the most dramatic change—in 1985 women's stress rates were 12% below men's, by 1991 women's stress rates were 29% above men's.¹⁷

- It is estimated that women constitute 80% of those who provide care, whether or not that care is paid, and whether it is provided in institutions or at home.¹⁸ There are significant differences in the nature of caring work provided by women and men, with women more likely to be involved in the provision of personal care and the management of caring.¹⁹

To date, most biomedical and clinical research has been conducted on men: it has been taken for granted that humans are male. Only because of legislation in the United States (but not in Canada) are women now routinely included in clinical studies. Even so, the United States General Accounting Office reports that there has been no change in the frequency of analysis of research results by sex, much less gender.²⁰ Canadian researchers found identical trends in their review of research studies and clinical trials at the University of Toronto.²¹ This speaks to a very slow rate of change, even with legislation and accountability frameworks mandating change. It also highlights the enormous need for capacity building and education about sex and gender analysis.

We are stymied not only by an unwillingness to consider how gender affects experiences, but also by how we might measure gender, and how we might measure the impact of programs and policies. Typically, when we consider the differences between women and men, we assume sex can be treated like any other variable, as if sex can be used as a proxy for gender. Another problem is that most programs and policies and the research that informs them, are almost totally gender neutral or gender insensitive. In studies into the provision of health services and the effects of health care reform on providers and recipients of care, women have, to a very large extent, been “overlooked, ignored or subsumed.”²² Consequently, it is difficult to ascertain exactly what consequences flow from policy changes. Gender insensitivity can occur in a few ways: we might fail to see if gender (not just sex) matters in how we analyze things, and in how we measure things.

■ Too often it is assumed that gender-based analysis addresses women's issues only. The whole point of GBA is to identify if and how programs and policies affect women and men similarly or differently—it is a question to be answered.

The Analysis Problem

According to Pat Kaufert, the problem in health care research is less often one of exclusion than of making women invisible.²³ This is often done in the course of data analysis, particularly in epidemiological studies. 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.²⁴ The majority of studies report age-standardized and sex-standardized findings using a population-based health information system.²⁵ It is true that standardization, or adjustment of population-based data, has the virtue of calculating a single rate that adjusts²⁶ for each age and sex group of a standard *population*, thereby resulting in improvements in the comparability of rates of different populations. However, such global statistics do not permit us to see the specific ways in which health experiences (whether we are talking about mortality or utilization of health services) manifest differently in the various *subgroups* of a population. We need sex-disaggregated data²⁷—data that is broken down by sex—to understand the gendered nature of health and illness experiences, including those related to health care utilization.

The Measurement Problem

Even studies that involve the calculation of sex-specific statistics can't capture why and how sex and 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 recipients and providers of care. Sex is a demographic characteristic that affects, for example, susceptibility to disease, need for surgery and the likelihood and patterns of accessing health care. We also need studies on the influence of gender, and this involves examining relationships of power, subordination and superordination. Most of our measures are totally inadequate for this.

In research on health system performance, the limited range of indicators used provides 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. And it is 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.

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. The data of choice seems to be population-based administrative data from the health services system. “Qualitative research is often relegated to supplementary roles ... such as planning or explaining quantitative research.”²⁸

To illustrate the limitations of administrative data, consider the 1999 report by the MCHPE on hospital bed closures in Winnipeg. Brownell and Hamilton report that 727 (24%) beds were closed in Winnipeg hospitals in the period between 1992/93 and 1997/98.²⁹ What were the effects of this hospital downsizing? 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 BC reached similar conclusions about the effects of hospital downsizing on elders' health care utilization and mortality rates.³⁰ Sheps et al. conclude that there have been minimal adverse effects associated with the reduction in acute care services. This change in services coincides with public policy goals of (and citizen preferences for) shifting care “closer to home,” and reserving longer-term hospital stays for those who are sicker. In an editorial regarding this BC study, Roos contends that all the media headlines about hospital downsizing and bed closures exaggerate the negative effects of this type of health care reform.³¹

I would argue that the impact of health care reforms, and in particular the shift of health care from institutions to the community and the home, have—for the most part—gone unexamined. These reforms, which continue apace as governments cut their financial commitments to the health care system, affect everyone, but I believe that they affect women more than men. Women are on the frontlines at home and in institutions. If caring work is transferred home, then women by and large will have to assume those responsibilities in addition to, or perhaps in place of, their other responsibilities in their families and in the paid work force. Similarly, professional nurses and other allied health workers, the majority of whom are women, have experienced work intensification, injuries and burnout as a result of health reforms.³² But by all counts, the gender effects of health care reform have been almost entirely ignored.

We need to view health care policy through a gender lens—that is, to identify how and why experiences differ for women and men. Without answers to these and similar questions, we cannot even begin to assess the effects of health care reforms such as hospital downsizing.

Chambliss has pointed out that, “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.”³³ This is the heart of the matter. Most policy research ignores sex/gender, is silent on its significance as a determinant, or treats sex/gender as if it is less important than other characteristics such as socioeconomic status. We need to determine not that sex/gender matters so much as that it doesn't matter before we dismiss the criticisms that many feminist researchers make about what gets measured and how. Until we do so, we are making policy decisions

blinded to the possibility that sex and gender do matter—to women, and to men—and we may be advancing policies in ways that disadvantage some segments of the population. And we'll keep running—like Alice and the Red Queen—but getting nowhere fast.



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How to Make Research Count

Crucial gender differences have been found in how women and men experience health and illness, receive and give treatment and intervention, and interpret experiences that enhance or reduce health. There are also critical differences in how women and men access the health care system, manage health care, work in health care and give care at home or elsewhere. Understanding these and other yet-to-be-discovered differences would directly benefit the health of Canadians.

Fully integrated health research is the only way to understand the impact of gender differences. In Canada, there is a long tradition in women's health research of pursuing integrated approaches. Now the British Columbia of Excellence for Women's Health has developed *Fusion*, a model that holds the promise of increasing the relevance of health research to women and men by integrating research methods, disciplinary perspectives and policy considerations.

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