

Why Put Gender and Sex Into Health Research?

1

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Putting gender and sex into health research design is a practice that is only recently being encouraged or adopted by researchers, their funders, and audiences. This chapter provides background and context on the rationale for and recent history of this late, but welcome, shift. It presages examples of health research that have incorporated gender and sex into design, and offers a commentary on the history and future of gender and sex in health research.

Why put sex and gender into health research? At heart, it is a matter of ethics to do so. As “every cell has a sex,” according to the Institute of Medicine (Wizemann & Pardue, 2001, p. 4), and every person is gendered (in some way), both sex (biological characteristics) and gender (socially constructed factors) must be woven into any health research that deems itself to be complete and/or relevant. Integrating these concepts reveals and reinforces their incredible significance in producing more accurate, effective, and relevant research findings. Hence, in order to improve health in humans (or animals), it is critically important to attend to both the biological and the social aspects of growth, development, illness, and recovery.

It is unfortunate that most studies on aspects of human health do not yet explicitly consider sex and gender in their design, data collection, or analysis. While progress is being made, examples of research articles, books, presentations, and products that do not distinguish along these lines are rampant, thereby making their results less useful, and sometimes useless.

Currently, the concepts of both sex and gender (and their relationships, contexts, and meanings) are routinely overlooked, misused, misunderstood, confused, or conflated in health research (see Fishman, Wick, & Koenig, 1999, for a discussion of the use of these terms), creating a kind of underlying chaos in the existing health literature.

Most disconcerting, perhaps, are researchers and research users who do not notice this gap, and consequently acritically apply gender- and sex-blind results to all people, wherever they are on the sex and gender continuum. These practices involve health promotion, diagnosis and treatment of diseases, clinical practices, therapeutic choices, program design, health system organization, and health and social policies. These practices also influence the designing of subsequent research studies.

At best, these conflations and oversights lead to practices that are just approximate and neutral. At worst, however, they can cause or perpetuate harm, pain, or inequity.

Ultimately, a generic approach to health research when these essential distinctions fail to be made in the design, analysis, or transfer of publicly funded research is simply unethical. In an age when knowledge transfer and translation is *the* critical path for funders, members of the public, and practitioners, how can any confidence be ascribed to health research results that do not comprehensively consider, measure, analyze, and account for both sex and gender, such fundamental aspects of human life? This rhetorical question underpins the enterprise of doing current, effective, and ethical research.

But putting sex and gender into health research is a complex task as our understanding of these concepts and the context of the health research enterprise has evolved considerably over the past few decades, and promises to continue to evolve. In addition, both sex and gender are concepts that are tightly interrelated, exist on continua, and, simultaneously, *interact iteratively* with each other. Not to mention, these concepts exist in an important web of influences on health and well-being, such as ethnicity, culture and race-related factors, age, ability, income, education, housing, and literacy, affecting the lives and bodies of people and being affected by them on micro to macro levels.

“Fault Line” of Gender

Apart from these obvious health impacts of doing health research differently, there is a critical social context in which these practices exist. Most societies are built and maintained along a “fault line” of gender (Papanek, 1984), and most societies have historically developed on a scaffold of patriarchal assumptions and practices. With the reemergence of feminism in the 1960s in many developed countries, a robust women’s health movement

emerged, addressing these assumptions and practices. Women's health advocacy engaged with multiple issues including roles, labor force participation, sexism, and violence against women. However, a robust section of the second-wave women's movement centered on health issues.

The women's health movement focused its energies on the body and women's control over it. On the care and clinical side, women complained about sexism, paternalism, and overmedicalization with particular emphasis on the appropriation by male doctors of sexual and reproductive issues, including childbirth. Women's health advocates also called for an end to oversights and omissions in both clinical practice and research, making particular note of the omission of women in clinical trials, all the while decrying gender neutrality and blindness that resulted from having too few women in science and medicine. It is in this context that the recent developments in the field of sex and gender in health research have emerged (Greaves, 2009).

The arguments began to build for changing health research. By the 1990s various countries were grappling with arguments for changing the approach to reflect sex and gender. The arguments included the issue of biological "differences," making the point that women's and men's bodies are different. Social differences were increasingly evident as well, with more and more social scientists illustrating that being male and being female are gendered experiences and, relatedly, that femininities and masculinities have varied but palpable meanings.

There was an important political dimension as well. At bottom, there was an argument for redress, noting that research on women, with women, and by women had been overlooked and needed rebalancing by attention to sex and gender and indeed, specifically, women's health. The reasons range from social justice and equity arguments to error rectification. It became clear that mistakes had occurred, and could continue to occur, when research on men was applied to women.

The response to the AIDS epidemic in some countries in the 1980s marked a key turning point for gay men's health. More latterly, broader issues around men's health have surfaced, and a nascent men's health movement has emerged. In part driven by the example of documenting and theorizing women's health, some men's health researchers have focused on the impact of masculinities on men's health behavior and their interactions with health systems. Others have unearthed new knowledge and funding for sex-specific health issues such as prostate cancer, bringing attention to such male-specific disease in line with the huge public attention to issues such as breast cancer for women.

Separately, a broader men's movement has often reacted to funding and attention that have emphasized both women's issues and women's health. These initiatives have often made the political point about including men as well as women in sex- and gender-specific initiatives, funding, and programming. The men's movement has focused on issues such as custody and access for divorced fathers, along with high-level attention to men's health.

In the context of these cultural shifts that are de-emphasizing patriarchy in favor of more liberal, equitable organizational power systems (clearly occurring at faster rates in some societies than in others), the range of issues to consider in analyzing and measuring sex and gender is dizzying. If sex and gender interact to create health, and are affected by cultural and temporal factors, how do we proceed in putting sex and gender into health research? How do we measure these synergistic effects? Further, how do we capture these concepts, processes, and relationships to pin them down?

Recent History of the Concepts of Sex and Gender

At the outset of the “second wave” of feminism in the 1960s, just discussing the influence of sex on health was novel. Sex, then, became the label and concept taken into the field, and represented both biological and social controversies and agreements. Given this stance, most of the early discourse was focused on “sex differences” (between males and females, men and women) and underpinned a range of requests for sex-disaggregation of data, differential treatment of women in clinical practices, and consideration of social issues such as “sex roles” and “sex-role socialization.” As can be seen from the list of concepts and labels below, the concept of gender followed, introduced by social scientists. Building on emerging notions of gender, the stage was set for an emerging differentiation of sex and gender as concepts and the recognition that both matter to women’s health and, ultimately, men’s health.

This differentiation was not evenly adopted across disciplines, fields, languages, and countries, however. This problem has been well described (Fishman et al., 1999) but, unfortunately, persists to this day. Nonetheless, both terms have been adopted in the literature and common discourse, even if used inconsistently between disciplines, or with different intentions. As the concepts of sex and gender became further developed, it emerged that a *differences model* was not accurately reflecting a continuum, or, at the very least, overlapping sets of characteristics that comprise sex and gender in human populations. Hence, the notion of *influences* of sex and gender captured this shift, along with the notion that certain *factors* such as bodily characteristics or social circumstances could affect human health.

Hence, the following linguistic layers are evident, at least in the North American context. While these layers represent shifts in thinking, and increasing sophistication, there are still uses for some of these early terms in certain circumstances as they offer precision to the field.

- Sex
- Sex differences

- Gender
- Sex and gender
- Sex and gender differences
- Sex differences and gender influences
- Sex- and gender-related factors

These evolving shifts in conceptualizing matched, reflected, or inspired a set of different analytic frameworks. As mentioned above, the notion of “sex differences” called for sex stratification, differentiation, and disaggregation, all techniques that indicated support for *comparing* men and women, or males and females. This assumed that the human population could be neatly divided into two, a binary or dimorphism that is no longer supportable. It also assumed that unless there was a “difference,” there was unlikely to be a problem. This thinking was based on simple notions of equality, not the importance of equity or equal opportunity for health, and did not reflect evolving thinking about the continua of sex and gender.

Once the term *gender* was introduced, it became clear that a more complex process would be required to incorporate its full meaning, and gender analysis was born. Gender analysis frameworks stress *processes* of critical thinking to interrogate gender, and do not typically suggest concrete measures (see Clow, Pederson, Haworth-Brockman, & Bernier, 2009). Highlighting critical appraisals of gender encouraged identification of situational and temporal characteristics across cultures and time, entrenching gender as a social process. Ultimately, gender analysis surfaces the relational issues between males and females, men and women, or girls and boys in the context of social institutions.

Gender was, and is, a complex concept and social process. Many disciplines engaged in health research do not address such social scientific processes in training or practice. Perhaps because of this, gender did become conflated with sex in some discourses and disciplines. More troubling and distracting, gender became conflated with “women” in some political and policy contexts, perhaps to mask a focus on women when that proved unpopular politically. Hence, gender and health or gender concerns were widely interpreted as pertaining to women or women only. Once gender became more accurately and widely understood, it also had the effect of conflating men’s concerns with women’s concerns, a disservice to both women’s health and men’s health as explicit attention is needed to both.

In addition to these difficulties, gender, as a concept in health research, has had a varied ride in the past 20 years, as it is both more complex and resistant to measurement than is sex and more broadly and inaccurately used. Attempts to quantify gender are few as most scientists perceive gender as a multipronged concept and a social process that is tightly tethered to its context, thereby resisting universal measure. It has even been suggested that sex and gender need to be merged conceptually and

measured accordingly, given their strong interactional component (see, for example, Phillips, 2005).

Nevertheless, several analytic frameworks contributed to our growing understanding of gender in health, notably the *determinants of health* and *social determinants of health* frameworks. These frames identified gender as a determinant of health, giving the field a strong boost. As thinking evolved, it became evident that the determinants of health operate together to create health, leading to new thinking about the necessity to indicate a clear and unambiguous incorporation of diversity into gender-based analysis. More recently, the concepts of health equity and inequity, identifying *opportunities for health* as the key measure, have helped to create actionable goals addressing diversities and disparities in health status. Finally, during all of this, more theoretical work on intersectional-type analyses has also emerged, identifying the myriad of features, factors, and processes that contribute to health, and contextualizing gender within those frameworks. These frameworks, more or less in order of emergence, are as follows:

- Sex stratification, differentiation, and disaggregation
- Gender (based) analysis and sex and gender (based) analysis
- (Social) Determinants of health
- Sex, gender, and diversity (based) analysis
- Disparities, (in)equities of health
- Intersectional-type analyses

The concept of diversity has had its own language evolution that has, in addition and by necessity, been different in different countries and regions. Over the past few decades, language, terminology, thinking, and a range of social and political events and movements have affected how diversity is interpreted, named, and understood. Terminology has also been determined by jurisdictional decisions about collection of census or other population-based data, resulting in different terms and classifications being used across jurisdictions, making comparisons difficult. In addition, there is growing imprecision as self-descriptions and multiple identities are measured. The concept of classification is a social construct, and many critics therefore debunk all efforts to collect such data. Nonetheless, relevant to health and other social opportunities and analyses, the following terms have been used and evolved over time:

- Race
- Nationality
- Minority group (visible or not)

- Ethnicity
- Ethnocultural identity
- Foreign born
- Indigenous
- Immigrant, migrant
- Racially classified social groups

Many of these terms have been variously either self-descriptions or externally imposed. Race, ethnic, and cultural labels are often contentious and contested. Nevertheless, in health, there is also often an interest and a need to identify health concerns, diseases, treatments, or policies that have a particular effect on groups according to their biological and social characteristics. Sometimes these requests are made by the group itself, seeking information; at other times they are descriptions of findings published as relevant to a particular group. There has been legitimate worry about such categorization being used for negative, prejudicial, and discriminatory purposes. However, these fears are being balanced by need and right to know as new techniques, knowledge, and technologies are resulting in new knowledge about genetics and other biological processes that shed light on difference. What is important, and again increasing the complexity of measurement in health research, is that many of the factors affecting diversity and health are in fact processes, such as the following:

- Biological processes
- Discrimination
- Experiences of sexism, racism, and heterosexism
- Identity formation
- Self-descriptions
- Labeling

This brief description of some of the key elements in evolving thinking about sex, gender, and diversity over the past several decades underscores the constantly evolving nature of this field. It also explains, to some extent, the emergence of the various fields of study listed below:

- Women's health
- Gender and women's health
- Gender and health

- Now (at least) three main fields:
 - Gender and health
 - Women's health
 - Men's health

Not surprisingly, the fields have multiplied and get more, not less, specific.

These stages of categorizing thinking in health reflect both political and sociological trends as well as their influence on global health organizations. As well, they represent the growing specificities and sophistication with which theoreticians and methodologists have approached these topics. This is not to ignore the nascent and emergent areas of study of intersex and transgendered and transsexual health (which, not incidentally, serves to starkly illuminate the complex and fluid conceptual issues surrounding sex and gender), but rather is to identify the areas affecting the majority of the human population.

Changing Practices to Support Sex and Gender in Health Research

Ultimately, the most compelling arguments for including sex and gender in health research became the ones made about ethics and the quality of science. Slowly but surely better science has been seen to include sex and gender, in the interests of increased validity, reliability, generalizability, and completeness. Without even seemingly getting “political,” acknowledging past patriarchal influences, uneven funding practices, or even lack of interest, agreement about improving the quality of science is something that all responsible leaders and researchers could support (Greaves et al., 1999).

These slow and emergent shifts in thinking have manifested in the development or modification of research funding practices and organizations, or in the development of strategic links between policymaking and research. In Canada, for example, sex and gender analysis is a required element in research proposals to the Canadian Institutes of Health Research (Spitzer, 2006), and in the United States, evidence of attention to women, children, and minorities is required in research proposals to the National Institutes of Health (1993). In Canada, this effort is complemented and supported by a federal policy requiring gender-based analysis in policymaking across government, which was enacted in 2000 by Health Canada. This latter policy has put pressure on research users, in this case federal policymakers, to consider a wider range of issues and variables connected to sex and gender before making social, health, or economic policy. Internationally, these trends fit with a commitment to gender analysis at major international agencies, notably the World Health Organization (2002).

However, all of these initiatives and directives need to be understood in context and with caution. Two illustrations from North America highlight different approaches to institutionalizing gender analysis. The federal gender-based analysis policy in Canada was audited by the Auditor General in a report issued in 2009. This report indicated that compliance with this policy was minimal across seven chosen departments including Health Canada. Even more troubling is that even when it was performed and gender impacts were analyzed, there was no indication that *the analysis was considered* in the development of policy decisions or assessed and reported to the Cabinet in policy documents (Auditor General of Canada, 2009).

A very different approach was taken in the United States, where the General Accounting Office analyzed compliance to the 1993 *mandatory* policy requiring research proposals to include women, minorities, and children in research funded by the National Institutes of Health (NIH), or else justify why not. Its 1999 assessment indicated that while there was 97% compliance with the directive for inclusion in the year 1997, there remained a strong need for production of data that were going to lead to valid analysis by sex and gender, resulting in specific additional recommendations regarding the necessity for analysis (General Accounting Office, 2000).

In countries such as Australia and Canada, strategies to guide policy-making in gender and health have been developed. Most recently, in Australia a men's health strategy has been developed to parallel ongoing strategic activity in women's health. Over the years, many of these strategic developments in policymaking have relied on simplistic sex differentiation between categories of men and women, with less attention to gender and its effects, or the differences among women or men. Clearly, as all of these organizational initiatives and directives show, there is a long and rocky road between directives to improve either research or policymaking and effective results in the field of gender and health.

To support these institutional and organizational changes, capacity building for both researchers and research users has been required in the provision of tools, primers, and books. Research users can be frustrated in incorporating gender into policy and program development if inadequate or incomplete research exists and issues of gender and sex are unacknowledged or unexplored. To remedy this, the Canadian primer *Better Science With Sex and Gender: A Primer for Health Research* (Johnson, Greaves, & Repta, 2007) was recently released. This primer sets out in simple terms the challenges of incorporating sex and gender into health research, suggests some methods and options for starting out, and illustrates the importance of doing so. In that spirit there have been numerous attempts to outline gender analysis both at national and at international levels. There is a hunger among researchers, trainees, and

well-established researchers alike, as well as research users, for more examples and information, and more support for experimentation and conceptual development.

GOING FORWARD WITH SEX AND GENDER AND HEALTH RESEARCH

Given the complexity of the tasks in putting sex and gender into health research, what are some reasonable goals going forward? Shall we continue to address the different language usage by discipline, culture, and place, and over time? Can we get agreement on definitions? Do we need to? Can we ever accurately measure sex and gender and their interactivity? What would a synthesized measure of both look like? Is the synergistic effect greater than either? Is this quantifiable? Is it better captured with qualitative or mixed-method research? Do these questions only apply to humans? And further, how do we measure diversity and its interaction with sex and gender? What influence do intersectional-type analyses have on the way sex and gender are integrated into health research? How will scientific and technological advances herald the potential for “postgenderism” (Dvorsky & Hughes, 2008) where the material bodies of individuals are so diverse or modified by technology or interventions that gender becomes a malleable and possibly elusive and yet liberating concept? These and related questions are increasingly top of mind for health researchers interested in gender, sex, and health.

As important, though, are the practical and advocacy goals inherent in this area. How do we generate more interest in sex, gender, and health research? Which arguments will resonate with the widest group of researchers, students, and funders? What will training look like? And finally, how can we institutionalize sex and gender in health research in more universities, hospitals, health authorities, governments, and countries? Can we encourage a surge of scientific advocacy to require sex and gender analyses at proposal development, at peer review, and in analysis and reporting in scholarly and nonacademic writing? Can we create such a demand in users of research for these very basic issues to be adequately addressed that ultimately all health research will acknowledge and measure the effect of sex and gender in human health? All of these questions and challenges underpin this field.

The design of research studies cannot practically be separated from knowledge translation activity. There are many points on the continuum of developing research when key decisions get made, and where investigators can either fail or succeed in producing sex- and gender-relevant research. These include decisions about how to generate and frame research questions, objectives, goals, or designs. Do these processes have consideration of sex and gender built in, and do they, ideally, engage with

research users from the beginning? Does the research design assume that simple sex-based disaggregation of data based on the binary categories of males and females, men and women, and boys and girls is enough? Does the research design limit itself to categorical sex-based classifications with no overlay of gender analysis or explanation or data collection about gender? Or worse (though, as we have seen, common), does the research take sex and/or gender into account, collect the data, and fail to analyze and report such findings?

So why put sex and gender into health research? The utility of sex- and gender-based health research is in its contribution to improving understanding of all aspects of health, disease, treatment, and health system design and policy. Ultimately we aim to acquire more knowledge and information on the influences of sex and gender on health. In the process, however, it is important to generate more precision in sex, gender, and health research by evolving more accurate and complex measures of sex and gender. This requires that we engage with a range of disciplines and highly conceptual and theoretical work in order to fully understand all the components of gender and their implications in human life.

While perhaps any step on the road toward full sex and gender integration into health research is to be encouraged, the challenges are to embrace all aspects of this journey and to become exemplars and mentors to both colleagues and students. The notion of automatically asking whether or not a piece of new knowledge (or old, for that matter) applies equally and equitably across the spectrum of sexes and genders, in a range of diversities of bodies, practices, identities, ages, locations, and geographies, is new. It is essential to support a burgeoning field, attempting to make this kind of question automatic, and, ultimately, answerable.

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