
Women's Health: Librarian as Social Entrepreneur

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ABSTRACT

It may take up to two decades before research findings become routinely used in clinical practice (U.S. Department of Health and Human Services, 2001). Librarians are uniquely positioned to maximize the accessibility of research. The author believes that research about gender biology and gender medicine needs to be integrated into clinical practice sooner than later, and that librarians can play a key role in connecting users with research. Utilizing the entrepreneurial approaches, techniques, methods, strategies, and tactics that are used for packaging and promoting their information products and services for social purpose, librarians can become social entrepreneurs. GenderBiology.net, a gateway to news and resources about gender biology and gender medicine, was created to assist information and health care professionals and consumers in this endeavor (Allison, 2006). This article provides an introduction to gender biology and medicine with selected events leading up to the concept of gender-specific medicine, as well as specific ways that librarians can become important players in getting gender-specific biomedical research information translated to real world application.

INTRODUCTION

Libraries provide information on a wide range of topics and opinions for patrons to seek and use as they choose. Although librarians may provide patrons with instruction and tools to discern between reliable and questionable sources of information, they do not advocate agendas concerning particular information their patrons have access to. But are there oc-

casions when librarians should go beyond providing information, to use library resources and services for advocacy?

When the provision of biological, physiological, and medical information is part of a library's repertoire of resources and services, advancing current research, especially if it will accelerate diffusion of new life-altering information relevant to health care innovation, can hardly be considered illegitimate. In fact, some areas of research may be so significant that it would be unethical not to intervene and encourage awareness and use. Gender-specific medicine is such a topic.

In library work, information may be identified of such profound importance that the librarian wants to do more, needs to do more, indeed finds it ethically imperative to do more to assure that this information is available, recognized, and *utilized in decision making*. Such is the case with current leading research regarding women's health. The study of differences in the biology and physiology of men and women, known as "sex-based biology," is yielding important knowledge about gender differences at every level—cellular, molecular, and organismal (Society for Women's Health Research [SWHR], n.d.b).

Physiological differences between the sexes affecting health can be found well beyond the reproductive organs (Legato, 2004). Sex-based variations have been found related to the heart, lungs, gastrointestinal system, immune system, nutrition, drug metabolism, infections, and aging; the list only continues to grow (Legato, 2004). These biological differences influence how women and men each exhibit illnesses and react to drugs and therapies. The "science of the differences in the normal physiology of men and women and of the way in which they experience disease" is known as "gender-specific medicine" (Legato, 2003, p. 1). Gender-specific medicine is shattering assumptions and myths about how men and women experience health and disease, and is creating a body of work on which to practice truly evidence-based health care for both genders.

Of course, variation in gene expression between sexes is expected in the reproductive organs. But the concept of such variation in non-reproductive organ tissues, particularly as they relate to disease manifestation, has not been considered until fairly recently. Yang et al. (2006) unexpectedly found that there are significant differences in gene expression between sexes in brain (13.6 percent), fat (68 percent), liver (72 percent), and muscle (55 percent) tissues. Many of these genes have also been associated with sex-biased diseases (Yang et al., 2006). This may well explain sex differentiations in physiology and disease response that a growing body of research is now finding.

Sex-based differences may affect responses to a drug, such as absorption, distribution, metabolism, and clearance (Bren, 2005; Jochmann, Stangl, Garbe, Baumann, & Stangl, 2005; Schwartz, 2004). A good exam-

ple of this is differences between women's and men's hearts. Due to gender variations in cardiac electrophysiology, women are at a much higher risk for developing a deadly arrhythmia known as *torsades de pointes* (Tdp) than men (Arya, 2005; James, Choisy, & Hancox, 2005; Pham & Rosen, 2002). These differences in cardiac electrophysiology may put women at risk for lethal arrhythmias by drugs that prolong cardiac repolarization (Huang et al., 2004; Rosen & Pham, 2004). In fact, of ten prescription medications withdrawn by the FDA between the years of 1997–2000, eight posed greater risks to women; three of which “induced potentially fatal cardiac arrhythmias in women more often than men” (U.S. General Accounting Office [GAO], 2001a, 2003).

Drug effects may be related to a number of factors, such as body size and body composition (Bren, 2005; Jochmann et al., 2005; Schwartz, 2004). One factor may be an enzyme called cytochrome CYP3A, which is involved with processing a number of drugs—women have more of this enzyme than men (Bren, 2005). With a liver tissue genetic variance of over 70 percent between the sexes (Yang et al., 2006), the potential for significant variation in the metabolism of drugs and drug effects between sexes for the heart and other organs is readily apparent.

Just as important, if not more so, this research is giving voice to women regarding their health experience. How many women have experienced or have known someone who has experienced frustration when they tried to relay their symptoms and their feelings to a health professional only to be given some invalidating response, such as they just needed to relax or that nothing was wrong? Having one's experience relegated to imagination, fabrication, and illusion often enough, perhaps over a lifetime, can create a self-image of being ineffectual, insignificant, and lacking self-worth. And yet, research is showing more and more that there is validity to women's health experience, that there are physiological reasons for their symptoms that can be measured through scientific inquiries.

Health care should be based on the results of this information—evidence-based. Despite advances, women still suffer from neglect even when cared for using conventional standards. To receive treatments and medications based on current research findings is even more of a challenge. Only when the newest gender-specific research findings are widely available will women be given truly appropriate and therapeutic care. Librarians are in a critical position to help integrate these findings into the mainstream by using their knowledge-management expertise and through their public service roles. Librarians who have personally experienced a lack of voice in the health care system or have had a loved one who has may be even more compelled to advance the latest news about gender-based research. These reactions can be the beginnings of social entrepreneurship.

SELECTED EVENTS LEADING UP TO THE CONCEPT OF GENDER-SPECIFIC MEDICINE

By and large it has been assumed that, barring the reproductive organs, physiological and disease processes are exhibited the same way in men and women. For the most part, the research on which medical care has been based was done only on men. A protectionist agenda for human research participants has been in place since the end of World War II, with the culmination of the Nuremberg Code after the horrific Nazi experimentations were exposed (Mastroianni, Faden, & Federman, 1994). Despite the best of intentions and policies since WWII, many research abuses of patients took place, such as the injection of live cancer cells into human beings without informed consent and the withholding of known effective treatments (Mastroianni et al., 1994). The thalidomide and Diethylstilbestrol (DES) tragedies further motivated protectionist policies, particularly for women of childbearing age since they may be or might become pregnant and risk adverse effects to the fetus. The U.S. Food and Drug Administration (FDA) issued guidelines in 1977 that excluded women of childbearing age from drug testing regimens (Mastroianni, Faden, & Federman, 1994). In addition to protecting unborn children, women were not included in clinical studies because of their hormonal cycles, which made study design, methodology, and interpretations complicated. It was felt that men were more stable models to study. Generally women were seen as smaller versions of men, and it was believed that knowledge about physiological and disease processes in men could be extrapolated to women.

In the 1970's, a number of women began to question many social mores, including norms about their health and the health care system that had assumed and expected women to play a submissive role. The book *Our Bodies, Ourselves* (1973), a collection of papers by the Boston Women's Health Book Collective, helped women learn about their bodies by providing information not available elsewhere at the time. This groundbreaking work empowered women to take an active role in their interactions with medical professionals and institutions. Women began to see other women's experiences as valid sources of information. They began to look critically at medical professionals and institutions, and to question the status quo. They influenced women to become active participants in their own health care, a concept that has inspired numerous improvements in the health care system. Their work, including updates of *Our Bodies, Ourselves*, continues to this day ("Our Bodies," 2006).

Timeline of Selected Events Fostering Gender-Specific Medicine Research

1983

Public Health Services [PHS] Task Force on Women's Health Issues (1995) was established by Assistant Secretary of Health, Dr. Edward N. Brandt, Jr. (Pinn, 1999).

1985

Public Health Services Task Force on Women's Health Issues recommends expansion of biomedical research to women's health areas (Pinn, 1999; PHS, 1985).

National Institutes of Health (NIH) adds a policy to include women in medical research (Pinn, 1999; Legato, 2002; NIH Office of Extramural Research, 1987).

1987

NIH policy urging the inclusion of women in medical research was incorporated into the 1987 *NIH Guide to Grants and Contracts* (NIH, 2005; Legato, 2002; NIH Office of Extramural Research, 1987; Pinn, 1999).

1990

The Society for Women's Health Research formed to promote the study of sex differences and inclusion of women in medical research ("How Far," 1999; SWHR, n.d.b).

Requested by the Congressional Caucus for Women's Issues (Advisory Committee on Research on Women's Health, 2005; NIH, 2005), a GAO report (1990) was done and concluded that the NIH policy to include women in biomedical research was inadequately implemented.

Women's Health Equity Act was introduced by the Congressional Caucus on Women's Issues and the Society for Women's Health Research to order the inclusion of women and minorities in medical trials as well as an office for women's health research (SWHR, n.d.a).

NIH created the Office of Research on Women's Health to support and coordinate initiatives to include women in medical research (Legato, 2002; Pinn, 1999; GAO, 1990).

The U.S. Department of Health & Human Resources Office (HHS) created the Office of Women's Health to coordinate women's health research in HHS agencies and offices (HHS Office of Women's Health, 2005).

The NIH Office of Research on Women's Health (1992) convened a hearing and workshop in which over ninety organizations participated, culminating in a report of recommendations for a comprehensive, multi-disciplinary approach to research concerning women's health across the lifespan that served as a foundation for NIH's research agenda.

1992

A GAO report (1992) found that the FDA did not have representative populations of women in the majority of drug tests, and that when they did, the results were not analyzed by gender.

The FDA created specific guidelines to allow women of childbearing age to participate in drug testing, along with its expectations for the inclusion of adequate numbers of women in research and gender analysis of clinical research results (FDA, 1993).

The NIH Office of Research on Women's Health requested that the Institute of Medicine assess ethical and legal issues related to the inclusion of women in clinical research (Mastroianni et al., 1994).

1993

Effective September 1994, the *National Institutes of Health Revitalization Act of 1993* mandated into law the previous policy that urged women and minorities be included in clinical trials in adequate numbers for analysis of differences, and instructed the NIH to create guidelines and outreach efforts to fulfill the mandate (NIH, 1994, 2005; Simon et al., 2005).

1994

The FDA created its Office of Women's Health to assure that women were included in clinical studies and that data from these studies were analyzed for sex differences in safety and effects (Wood, 2005).

NIH revised its guidelines clearly stating that for projects to receive NIH funding, the research has to comply with NIH's policy: research plans need to include women and minorities unless there is clear and compelling justification not to do so—cost not being one of them. Furthermore, appropriate outreach must be done to secure participation of these populations, and projects need to examine these groups for differing effects, if any (NIH, 1994).

IOM published book *Women and Health Research: Ethical and Legal Issues of Including Women in Clinical Studies* (Mastroianni et al., 1994).

1996, 1997

NIH Office of Research on Women's Health convened a series of three regional meetings and a final national meeting (Beyond Hunt Valley: Research for the 21st Century) to explore issues relating to women's health (NIH, 1999). These forums culminated in an eight volume report that surveyed what was currently happening at the NIH regarding women's health research and provided recommendations for the next century, including the recommendation for research to understand sex and gender differences in health and disease states to utilize for prevention and treatment strategies (NIH, 1999).

1998

FDA amended its regulations to require data for gender, age, and racial subgroups along with inclusion of subgroup enrollment numbers in research annual reports (FDA, 1998).

2000

FDA created a regulation that allows research for life-threatening conditions to be terminated temporarily for participant exclusions based on reproductive issues (GAO, 2001b).

2000, 2001

GAO reports found significant progress by both the NIH and FDA in including more women as research subjects, but determined there was room for further improvement including the analysis and reporting of data regarding sex differences (GAO, 2000, 2001b).

NIH (2005) made their guide for grants and contracts explicit regarding analysis of data for sex differences and the reports of such data.

2001

With research funded by the efforts of the Society for Women's Health Research, the landmark report *Exploring the Biological Contributions to Human Health: Does Sex Matter?* was published by the IOM (Simon et al., 2005; SWHR, n.d.c.).

A FDA review concludes that men and women were represented proportionately in clinical drug trials, and that most labels include gender assessment but none provided alteration of dosage based on sex (FDA Center for Drug Evaluation and Research, 2001).

The GAO (2001b) found "women sufficiently represented in new drug testing, but FDA oversight needs improvement."

A U.S. House (2001) committee of conference believed that the FDA was paying inadequate attention to gender-based research.

FDA created the Demographic Information and Data Repository projects (DIDR), which would include clinical study data, review documents, and labeling details, along with product safety and effectiveness information (FDA Office of Women's Health, n.d.).

2003

NIH Office of Research on Women's Health Task Force on the Recruitment and Retention of Women in Clinical Studies (2003) sponsored a conference (*Science Meets Reality: Recruitment and Retention of Women in Clinical Studies, and the Critical Role of Relevance*) for the scientific community to review

progress and challenges since its inception in 1990, and found significant accomplishments had been made with inclusion of women in research studies with women participating nearly equally in numbers with men.

NIH reported that the “the scope and expansion of Women’s Health Research across the NIH has been remarkable” (Advisory Committee on Research on Women’s Health, 2005, p. 93).

GAO reports (2003) that women adequately were represented in drug tests but FDA tracking and compliance of such representation in FDA clinical trials was inadequate. Analysis of sex differences was not required, and dosage adjustment was not addressed for studies that indicated higher drug concentrations seen in people of lower weight—approximately 30 percent of new drugs.

2005

HHS found that substantial numbers of women have participated in NIH research studies (NIH, 2005).

Society for Women’s Health Research found that from 2000–2003, only 3 percent of NIH grants awarded were for research concerning sex differences, which denotes a decrease of 16 percent over those three years (Brush, 2005; Simon et al., 2005).

2007

Current NIH Office of Research in Women’s Health research priorities include “research on the effects of sex as a modifier of cellular and gene function” and genetic, molecular, and cellular sex differences in drug action (NIH ORWH, 2007, Section III).

WHAT’S THE PROBLEM?

Gender biology research is being conducted, but are the results of this research being incorporated into health care practice within a reasonable length of time? As one can see from the *Timeline of Selected Events* in the previous section, it has taken over a decade to make limited progress in getting women into biomedical research so that sex differences could be analyzed. Incorporating the results of this research into practice has similar challenges. In fact, basic research may take up to two decades before the findings become routine in clinical practice (HHS, 2001). In one study, it took nine clinical procedures an average of 15.6 years to go from their landmark trials with 0 percent use to a 50 percent rate of use: this entailed an average of 6.3 years for the knowledge to reach reviews, papers, and textbooks followed by an average of 9.3 years to implement that knowledge (Bala & Boren, 2000).

Why does it take so long for the diffusion of medical knowledge? The sheer amount of biomedical articles published grows exponentially. The list of journals included in the National Library of Medicine's database MEDLINE® numbers nearly five thousand; the number of articles published in these five thousand journals that would be of potential interest to clinicians can conservatively be considered staggering. It has been estimated that to keep up with the biomedical literature would require reading close to six thousand articles a day (Lundberg, 1992). In addition to a lack of time (Kalsman & Acosta, 2000), physicians cite a lack of specific information as well as too much information to scan as significant barriers to using electronic resources on the Internet (e.g., online journals, professional association Web sites, medical point-of-care databases, continuing medical education programs, and colleagues via e-mail) (Bennett, Casebeer, Kristofco, & Collins, 2005; Bennett, Casebeer, Kristofco, & Strasser, 2004; Bennett, Casebeer, Zheng & Kristofco, 2006).

As is the case for much research, there is a delay of time between the creation of knowledge about gender biology and the diffusion of that knowledge into health care practice. As emphasized in the previous section, much has been accomplished in respect to research relating to gender biology. But has enough progress been made? What does it take to get knowledge gained from the basic biological sciences into practice in the applied health sciences—from theory to actual use?

WHAT CAN BE DONE?

It is easy to find examples of successful diffusion of innovations (related terms: "dissemination of knowledge," "knowledge to action," "knowledge translation," "research translation," and "research to practice") all around us. There are also countless examples of equally important innovations that failed to be incorporated into widespread use. What fosters the acceptance and use of new knowledge and how can librarians help?

Tipping point

The first step to developing strategies that will push research into practice is to investigate what methods have worked in successful diffusion of innovations. Malcolm Gladwell (2000) provides such an analysis of change and notes compelling similarities in what nurtures it. Gladwell likens the spread of ideas, products, messages, and behaviors to the contagiousness of viruses and compares trends, transformations, and changes to epidemics. He identifies three characteristics of epidemics: (1) contagiousness; (2) little changes can have big effects; and (3) changes happen suddenly, not gradually (p. 9). He calls "the moment of critical mass, the threshold, the boiling point" when an idea "tips" into a social "epidemic" and spreads like wildfire as the "Tipping Point" (p. 12). Tipping Points follow three rules: "the Law of the Few, the Stickiness Factor, and the Power of Context" (p. 19).

The *Law of the Few* demonstrates that social epidemics are “driven by the efforts of a handful of exceptional people” (Gladwell, 2000, p. 21). The Law of the Few depends on “Connectors” who spread and connect people to new information; “Mavens” who accumulate knowledge and help people utilize that knowledge; and “Salesmen” who persuade people to use the information—they control word-of-mouth epidemics, translating “the message of the Innovators into something the rest of us can understand” (p. 203). Gladwell explains that just as “there are people we rely upon to connect us to other people, there are also people we rely on to connect us with new information. . . . [These are] information specialists” (p. 19).

How well the intended message impacts the intended audience depends on its *Stickiness Factor* (Gladwell, 2000, pp.19, 25). Presentation and structure of information can have an enormous effect on the message’s impact (p. 25). Finding ways to make the message remembered (stickiness)—even irresistible—can help promote contagiousness (p. 25).

Timing and environment are also important considerations when developing strategies that tip an idea into an epidemic. The *Power of Context* should not be underestimated; what works in one situation may not work in another. Gladwell’s examples are inspirational, and document how even small efforts can actualize important change.

Social Entrepreneurship

In diffusion of innovations research, change is affected by a “change agent” (Rogers, 2003). Rogers describes a change agent as “an individual who influences clients’ innovation-decisions in a direction deemed desirable by a change agency” (p. 473). Jensen (2005) states: “Identifying and solving large-scale problems requires a special kind of social change agent operating in the civil sphere.” The Skoll Foundation (2007) calls “society’s change agent” a social entrepreneur, a “pioneer of innovations . . . that benefit humanity.”

A concept first coined in the early 1990s, the definition *social entrepreneur* has yet to be standardized and has numerous variations in use (Mair & Marti, 2004). Many definitions combine an economic aspiration along with a social one. For instance, the Institute for Social Entrepreneurs uses Jerr Boshee’s definition “the art of simultaneously pursuing both a financial and a social return on investment” (The Institute for Social Entrepreneurs, n.d.).

Alvord, Brown, and Letts (2004) describe three variations in the concept of social entrepreneurship:

- Commercial endeavors are used to support social activities
- Activities center on social problems rather than commercial considerations
- Social innovations are used to catalyze short term changes into long-term sustainable ones.

Their research focuses on the latter variation of “social entrepreneurship as a catalyst for social transformation. . . . that creates innovative solutions to immediate social problems and mobilizes the ideas, capacities, resources, and social arrangements required for sustainable social transformations” (p. 262).

Expanding the definition of social entrepreneurship outside the business concept fits with the original meaning of the word *entreprendre*, which is Old French for undertaking a venture, either business or enterprise (Merriam-Webster Online, n.d.). A growing number of researchers do not confine the concept to a business entrepreneurship model with the main value being monetary only, but broaden the interpretation of the concept to include the value of social significance. Dees (1998) begins this exploration by describing social entrepreneurs as seeing “the social mission [as] fundamental” and “social impact is the gauge” with a “long-term social return on investment” being the goal (p. 4). He further describes social entrepreneurs as being bold, skilled, relentless, determined, innovative, persistent, visionary, exceptional change agents—a “special breed of leader” (p. 5). Bornstein (2004) sees social entrepreneurs as “transformative forces:”

People with new ideas to address major problems who are relentless in the pursuit of their visions, people who simply will not take “no” for an answer, who will not give up until they have spread their ideas as far as they possibly can. (p. 1)

LIBRARIAN AS SOCIAL ENTREPRENEUR

So how can librarians become *connectors* and make gender-specific health information, as Gladwell (2000) says, “contagious” to the point of an “epidemic”? As he explains, little changes can have big effects and happen suddenly (p. 11). One powerful method is word of mouth. Kent Seltman (2004), director of marketing at the Mayo Clinic, reports that in their surveys of patient satisfaction, 96 percent of patients state that they say good things to others about their experience at Mayo, and that they do so, on average, to forty-eight others. This demonstrates well the power of the word of mouth, particularly about information of importance to health consumers. No opportunity can be too small to have substantial impact in spreading the word.

Getting the word out about gender biology and gender medicine research is crucial to integrating the findings into health care practice. Librarians are uniquely positioned to maximize the accessibility of this research. Using the entrepreneurial approaches, techniques, methods, strategies, and tactics that are used for packaging and promoting their information products and services for social value, librarians can become social entrepreneurs.

To spread the word, librarians have a great many opportunities at their disposal to educate their patrons and affect change. Through reference service, cataloging practice, collection development, information literacy, and any number of other professional activities, librarians can make knowledge more accessible both through print and through word of mouth. Librarians can become advocates by using their research skills to:

- identify best practices;
- share relevant news stories and important research results relating to community initiatives;
- compile local trends data and other statistical information such as census data, demographics, morbidity and mortality data, and health status indicators. (Spatz, 2005, p. 455)

To become social entrepreneurs for gender-specific medical information, librarians must become educated about the topic. What is learned then can be used to educate patrons through a variety of initiatives.

Strategies for Locating Gender-Specific Medical Information

The process of educating oneself about any new concept begins with an understanding of terms relevant to the concept. Knowledge of these terms is essential to provide reference service, information literacy delivery, and information management including collection development and cataloging.

There are a number of terms used in the literature and by various organizations for the subject *gender-specific medicine*, such as *sex-based medicine*, *gender-specific care*, *gender-based medical research*, and *gender medicine*. Because the discipline is new, different terms may be used for the same concepts and the same word(s) for different concepts. Such overlap in the usage of terms can create confusion and make it difficult to find related research, as well as to understand it. The Partnership for Gender-Specific Medicine defines gender-specific medicine as “the science of the differences in the normal physiology of men and women and of the way in which they experience disease” (Legato, 2003, p. 1). The Institute for Medicine defines *sex* as “the classification of living things, generally as male or female, according to their reproductive organs and functions assigned by chromosomal complement;” and *gender* as “a person’s self-representation as male or female, or how that person is responded to by social institutions on the individual’s gender representation. Gender is rooted in biology and shaped by environment and experience” (Wizemann & Pardue, 2001, p. 17). A related area is *gender-based biology*, which also includes several terms for this concept, such as *gender-specific biology*, *sex-based biology*, and *gender physiology*. The IOM defines *biology* as “the study of life and living organisms, including the genetic, molecular, biochemical, hormonal, cellular, physiological, behavioral, and psychoso-

cial aspects of life” (Wizemann & Pardue, 2001, p. 17). Because gender-specific medicine is a new discipline with several terms that are used synonymously for the concept, it is necessary to cast a broad net to locate relevant information.

The Partnership for Gender-Specific Medicine at Columbia University (n.d.) is creating a database called GenCite[®], which will be useful to find research literature for this discipline. In the meantime, traditional scholarly databases, such as PubMed[®], the Cumulated Index to Nursing and Allied Health (CINAHL), and online library catalogs will be the main sources of information. When using any source, it is important to know if the source has a controlled vocabulary. “Gender specific care” is a CINAHL subject heading for “Care that is sensitive to sex-specific needs. General only; consider also MEN’S HEALTH and WOMEN’S HEALTH;” and “sex factors” for “Use when gender is discussed as a factor in relation to some specific subject or problem, usually a statistical concept” (CINAHL Headings, n.d.). Some of the Medical Subject Headings (MeSH) in PubMed assigned to gender-specific medicine articles include “sex factors,” meaning “maleness or femaleness as a constituent element or influence contributing to the production of a result;” and “sex characteristics,” meaning “those characteristics that distinguish one sex from the other” (National Library of Medicine, n.d.). Library of Congress Subject Headings (LCSH), which are typically used in academic library catalog records, include the terms “sex differences” and “sex factors in disease” for a number of gender-specific book and journal titles (Library of Congress, 2004). To find relevant information one must search using known terms and synonyms relevant to gender-specific medicine, such as those noted above.

The following subject headings for three major formal languages were identified from published titles on gender-specific biology and medicine:

Library of Congress Subject Headings (LCSH)

Gender differences

Sex differences

Sex factors in disease (“Sex factors” may also be a subdivision)

Women — Diseases

Women — Health and hygiene

Women’s health

Note: No “Health — Men” or “Men’s health”

Medical Subject Headings (MeSH[®])—Used for MEDLINE (PubMed[®])

Sex Characteristics

Sex Differentiation

Sex Factors

Women’s Health

Note: No “Men’s Health”

*Cumulative Index to Nursing and Allied Health Literature (CINAHL®)**Subject Headings—Used by CINAHL database*

Gender-Specific Care (since 2002)

Men's Health

Sex Factors

Women's Health

As these examples show, there are frequently variations among formal languages for the same concepts. Subject terms in one database can be useful keywords in another. As previously discussed, there are still several issues related to the terminology used for gender-specific medicine that are being questioned, and it may be some time before definitive terms are established. In the meantime, it is useful to know the current subject terms for published items in this area. It is interesting to note in the above examples that only CINAHL used the current term "gender-specific," which has the scope "Care that is sensitive to sex-specific needs. General only; consider also MEN'S HEALTH and WOMEN'S HEALTH" (CINAHL Headings, n.d.).

A word of caution—not all gender-specific medicine articles will include all, or sometimes any, of the currently used formal subject headings. When titles are identified, one should keep track of terms associated with the work, both formal subject headings and natural keywords. Periodically one can check Web sites and published works of known researchers to identify current research and the terms being used to classify this research.

Aside from the standard medical databases, there are many other sources that provide information about gender-specific biology and medicine. Reputable news databases such as Reuters News, EBSCOhost Newspaper Source, and LEXIS/NEXIS Academic Universe are excellent secondary sources of up-to-date information, as are news magazines like *Health*, *Scientific American*, *Science Magazine*, and *Science News*. There are several news Web sites and television programs that may have pieces or specials on recent biomedical research, including biological sex-differences. Reports of research in these sources can lead to primary sources of information. For instance, reports can be mined for names of researchers that then can be used to locate primary research articles. Author affiliations can be investigated to see if there are specific programs relating to gender biology or medical research, which can also lead to specific research findings. Press releases can be an effective way to get news to professionals, according to a new study by the research firm Outsell which finds that "the most used content type among knowledge workers for business purposes has switched to press releases" (Claburn, 2006). It is postulated that the increased prominence of press releases as a source of information is because they "are easier for people to get their hands on. . . . [They] are shorter and pithier. . . . and oftentimes free and come right into an

RSS reader" (Claburn, 2006). Finally, becoming familiar with the associations, centers, organizations, and government agencies involved with research relating to gender biology and gender-specific medicine and/or the dissemination of information is another excellent strategy to gain knowledge. Not only can one locate research findings on their Web sites, a great deal of information about activities of these groups can be found as well as names of researchers in the field.

Strategies for Disseminating Gender-Specific Medical Information

Once familiar with the topic, the librarian can integrate knowledge gained into the knowledge environment. All aspects of librarianship provide opportunities to promote information about gender-specific research.

Since gender-specific medicine is a fairly new area of research, collection development in this area can be a challenge. As noted earlier, it can take up to two decades for research to move from papers to textbooks to common practice (Bala & Boren, 2000; HHS, 2001). Medical books that cover health issues using gender-specific research have been sporadic, an early example being Legato's *The Female Heart* (1991). Such texts have increased slowly albeit exponentially in recent years. Books may focus on specific health topics using sex-specific research, or they may cover several health topics. There are books about gender-specific medicine that also include useful medical information related to sex-specific research. Some books are hybrids of conventional women's health (reproductive focus) and sex-specific medical information. There are some published works with titles that clearly indicate that they provide gender-specific information, such as *Principles of Gender-Specific Medicine* (Legato, 2004). The terms *sex differences* and *gender differences* along with the word *health*, *disease*, or a specific health or disease term are cues to look for in the title.

To identify relevant resources for the collection, librarians have many options. Reading reviews is critical. Belonging to professional listservs where collection issues are discussed will also provide the librarian with insight about which materials to purchase. If the librarian works at a research university, working closely with faculty in the field is essential. Scanning relevant Web sites, such as those of professional organizations, will often lead to new and cutting-edge resources that may be purchased for the collection. Additionally, the librarian can work with her acquisitions staff to include key publishers on approval plans. Finally, attending professional meetings and networking with other librarians will provide the librarian with ideas and information about making well-informed collection decisions.

Reference service—both in-person and virtual—can be a direct point of information access for the health care consumer or provider. Whether it is through the informed librarian or through reference resources, reference service is an important point-of-impact opportunity to disseminate

gender-specific information. A medical reference inquiry by a health care consumer is an opportune time to raise awareness about gender-specific knowledge

Particularly in the early phase of any research that is in the translation process, it is quite helpful to create tools that will help those seeking information about gender-specific biomedical research. The terminology in new areas can be diverse, as has been demonstrated earlier in this article. This situation is exacerbated by the multidisciplinary nature of this topic. Those blazing the trail can save patrons a great deal of time and energy by creating resources such as bibliographies, guides or pathfinders, and tutorials. Eventually the hope is that sex-based findings will become part of routine medical research and care. Until that day, there is a need to harness this knowledge and promote the findings in a way that fosters such inquiry. Guides, pathfinders, and tutorials are effective ways to do this.

Bibliographic databases are essential resources for discovering published literature. There are a number of useful ones for locating gender-specific biomedical research. Librarians working with patrons doing any type of medical research must know the intricacies of each of these systems in order to provide the best reference service. PubMed is the premier bibliographic database for identifying biomedical literature from MEDLINE, life science journals from PubMed Central, and selected life sciences articles from non-indexed general science and chemistry journals (National Library of Medicine, 2006a, 2006b). Indexed article records contain the controlled vocabulary Medical Subject Headings (MeSH). Currently the MeSH terms "sex characteristics," "sex distribution," or "sex factors" are typically seen with articles about sex-differences and gender-specific research, along with the headings "male" and "female," and/or "women's health," so doing a MeSH search should retrieve related article records. But this is not always the case. For instance, the phrases "sex differences" and "sex-based differences" are found frequently as part of article titles, so a basic search using the term "sex differences" may bring up records that do not have "sex characteristics," "sex distribution," or "sex factors" assigned as MeSH terms, an example being "Sex Differences and Genetic Associations with Myocardial Infarction" (Newton-Cheh & O'Donnell, 2004). Such articles cannot be retrieved when doing a search using the three MeSH terms characteristically assigned to articles on this topic. Whether in PubMed or other bibliographic databases, it is sound practice to use both the formal vocabulary as well as basic keyword searches of related terms to reduce the chance of missing relevant articles.

Biological Abstracts®, Current Contents Connect®, and Science Citation Index are other major bibliographic databases that index biomedical research journals, all products of Thomson Scientific. Biological Abstracts® is the major life sciences bibliographic database, covering topics related to sex-based biology in areas such as biochemistry, neuroscience,

and pharmacology. Articles indexed in this database are assigned broad subject areas called Major Concepts (MC) as well as five-digit subject area codes called Concept Codes (CC) to enhance searching topics; both can be searched directly in the record fields, or the MC/CC indexes can be browsed in Advanced Search mode. Major Concepts has no terms for “sex” or “gender” but it does use the terms “male” and female,” which are related to gynecology, obstetrics, reproductive systems, and urology. Biological Abstracts (n.d.) has a Concept Code (CC) 03510 for Genetics—Sex differences; its Scope is the “studies of genetically determined sex differences and sex differentiation.” Search results for this code are published from 1974–2000. This code was retired in the late 1990s when BIOSIS changed to automated CCs, which are created from terms assigned by the indexer making programmatic generation of this code unfeasible; using the search terms “sex differences,” “gender differences,” or “sex” are recommended to refine searches (C. Maurer, Thomson Scientific Customer Technical Support, personal communication, February 6, 2007).

Current Contents Connect is a multidisciplinary bibliographic database that includes a Life Sciences Edition Subset. There is no formal language thesaurus in Current Contents Connect or Science Citation Index Expanded™. Citation records include “Author Keywords,” which are searched in a Topic search, as well as “Keywords Plus,” which are words that emanate from cited article titles and are also searched in a Topic search. Science Citation Index Expanded is the renowned cited reference bibliographic database of scientific journals; it supports both standard and cited reference searching. Like Current Contents Connect, Science Citation Index Expanded does not have a formal language thesaurus, but utilizes “Author Keywords” and “Keywords Plus.” It also provides a “Subject Category” but this is based on the journal subject area rather than the article content (Science Citation Index Expanded, n.d.). It is assigned from a list of approximately one hundred Subject Categories: a number of categories include the term “medicine,” “biology,” or “physiology” but none of these specifically include “gender,” “sex,” or “women/men” (Science Citation Index Expanded, n.d.).

Although there is considerable overlap of indexed titles between PubMed, Biological Abstracts, Current Contents Connect, and Science Citation Index Expanded, each database has unique titles that would be missed if not searched. For instance, Biological Abstracts provided an article from the *Journal of Animals Science and Technology* not indexed in PubMed that would be important to someone who was interested in research about sex-differences related to endocrine-disrupters (“Effects of Phthalate/Adipate Esters Exposure During Perinatal Period on Reproductive Function after Maturation in Rats” from the *Journal of Animal Science and Technology*). Since lab animals such as rats and mice are utilized to study disease processes and responses, animal research literature may be

the only source of physiological information on a condition. Not searching Biological Abstracts would have missed such a unique article.

MedlinePlus.gov is a source of authoritative information for health care consumers provided by the National Library of Medicine and National Institutes of Health. Among the many resources available from this Web site are a medical encyclopedia, medical dictionary, information about drugs, and information from the NIH and other important sources for over seven hundred Health Topics. The "Women's Health" and "Men's Health" categories provide links to diseases and conditions, most at this time relate to the reproductive organs or issues but there are some links to sex-based biomedical information, especially information about heart disease in women. Although no one health topic focuses on gender-specific biomedical information, the "Women's Health Issues" and "Men's Health Issues" Web pages do provide access to some sex-based biology news and research. Doing a Medline Plus search on various phrases such as "sex differences" and "sex-based" did locate information in the various Health Topics categories and other resources, but a health care consumer using this resource would need to know what terms to use when doing a search.

Government intervention by the major institutes, agencies, and offices with prompting from women's groups such as the Congressional Caucus on Women's Issues and the Society for Women's Health Research led to many of the advances related to gender-specific medicine. These entities are important sources of information on the subject for both historical and current knowledge, and much information can be gleaned from their Web sites. See for example, NIH Office of Research on Women's Health, U.S. Department of Health & Human Resources Office of Women's Health and its National Women's Health Center [womenshealth.gov], FDA Office of Women's Health, Institute of Medicine, and General Accounting Office. Traditional government resources such as the *Catalog of U.S. Government Publications* (the online counterpart of the *Monthly Catalog of United States Documents*) and *Federal R&D Project Summaries* can be excellent sources of sex-based research utilizing the same strategies that produced successful search outcomes in bibliographic databases. Much government information is cataloged and available in universal bibliographic databases such as WorldCat, as well as academic and public library collections. Government documents librarians are experts in finding government information, and should be contacted when help is needed.

Bibliographic instruction can be an excellent opportunity to raise people's awareness about gender-specific research. Of course, one can conduct a library session on the topic of gender-based medicine and discuss specific strategies to find relevant information. Librarians can also use sex-based research as examples of and techniques for searching in almost any instruction session. Even though there may not be immediate need for such information by class attendees, using sex-based research ex-

amples during instruction sessions can raise the attendees' consciousness about this issue, which may be of use to future information quests.

The decisions health care consumers and providers make regarding their information needs are considerable. In assisting patrons through reference service or through library instruction, librarians need to be clear about their role and their responsibilities (Reference and User Services Association [RUSA], 2001). The purpose of providing access to medical information is *not* to provide medical advice, but to provide "complete and accurate responses to users' questions when possible and for guiding library users to the most appropriate resources for their information needs" (RUSA, 2001). The librarian must *never* respond to health care information requests that in any way could be construed as offering medical advice. To make this clear it is advisable that information resources contain a disclaimer. See examples posted on the CAPHIS Web site at <http://www.caphis.mlanet.org/resources/disclaimers.html>. Essential reading for librarians is the *Guidelines for Medical, Legal, and Business Responses* (RUSA, 2001.)

More subtle in its role for patron access, but just as significant as reference service, is cataloging practice. The bibliographic record in local resources and vendor bibliographic database products contains all details of published works that are indexed in them. If these records do not include terms that describe the piece accurately and completely, the item may not be found. Formal subject headings are powerful points of access in the bibliographic record. Knowing the formal terms used for various bibliographic resources can enhance search results. As terms become formalized into controlled vocabularies, a standard of use for catalogers will take place. For now, since the terms are used inconsistently in published works, catalogers would be wise to enhance bibliographic records with the subject headings mentioned above as appropriate.

In the end, the goal is to make health care consumers as autonomous as possible. This includes being responsible in their information pursuits. MedlinePlus has links to several resources to educate the health care consumer about how to evaluate the information they find. The Consumer and Patient Health Information Section of the Medical Library Association also provides guidelines for consumers on how to choose health books (<http://www.caphis.mlanet.org/resources/bookselect.html>).

Additionally, CAPHIS (1996) articulates several roles for the librarian in consumer health information and patient education in the areas of collection management, knowledge and resources sharing, advocacy, access and dissemination of information, education, and research, such as the following:

- Networking with other individuals, organizations and agencies to facilitate resource sharing of CHI [consumer health information]/patient education materials

- Working with the institution and the community to develop informational and educational programs related to health issues, e.g., weight control, living wills, etc. The librarian often plays a special role in identifying materials, locating speakers, etc.
- Alerting health educators to areas of concern to the public for future program development
- In cases where the institution has a patient education program, working as a member of the interdisciplinary team to meet the informational needs of the programs
- Acting as advocates on the local, national and international levels to promote open access for the public to health information
- Creating and compiling CHI and patient health information resources and/or pathways that are accessible via the internet and other national information networks
- Providing a current awareness service for health professionals about new CHI and patient education materials
- Creating awareness for health professionals regarding the health information needs of consumers.

AUTHOR AS SOCIAL ENTREPRENEUR = GENDERBIOLOGY.NET

Since the early 1990s, the author has long awaited the integration of gender-based biological research into mainstream practice. In her role as an academic librarian, the author keeps abreast of the latest medical research, including sex-based biomedical research. But in the *real world* when she or family and friends seek medical attention, she does not see this research being used in practice. Understanding how difficult it is to push new research into actual practice, the author wondered how librarians could connect research to those who needed it most.

Librarians are knowledgeable about the barriers of healthcare professionals and consumers to the use of new research findings. Librarians can design and develop resources to overcome these barriers and enhance translation of research into clinical practice. By addressing related issues such as lack of time, lack of specific information, and too much information to reasonably survey (Bennett, Casebeer, Kristofco, & Collins, 2005; Bennett, Casebeer, Kristofco, & Strasser, 2004; Bennett, Casebeer, Zheng & Kristofco, 2006; Kalsman & Acosta, 2000) the access and use of information can be advanced.

With this in mind, the author developed a Web site and news blog, GenderBiology.net, as a gateway to news and resources about gender biology and gender medicine for healthcare consumers and professionals as well as information professionals. A *living* bibliography, it provides access to information about associations, organizations, agencies, and research centers; book and journal lists; congresses, conferences, meetings; databases; government documents; history; listservs; online courses; and Web

sites. GenderBiology.net also relays reports from reputable sources about various gender-based biology and medical news, with links to primary research such as PubMed article records when feasible. Exploring the contents of this Web site will provide librarians and others with information to develop a strong, comprehensive background on gender biology and medicine. Librarians can use this site to find information for reference questions, collection development, and related support. Information garnered here can be utilized for social entrepreneurship efforts, both in one's roles as a librarian and as a health care consumer. The author welcomes recommendations for content, which can be emailed to info@genderbiology.net.

CONCLUSION

A growing body of research is revealing sex differences in health and disease processes. Moving current research to use in clinical practice can take decades. Until recently, most biomedical research was done on males, because normal female hormonal fluctuations made studies more complicated and difficult to analyze, and there was potential harm for unborn babies of women who did not suspect they were pregnant. Thanks to advocacy by women's groups and government bodies in the early 1990s, research began to be done using females. Results of such research validated concerns that women did exhibit health and disease differently. The government took the lead, and created policies and agencies to ensure that research incorporated women as well as men. Nonetheless, government bureaucracy has proven a formidable challenge in getting inclusive research policies into practice; therefore, research on gender medicine is still slow to translate into clinical practice. There has been progress and the gender-specific biomedical literature is growing. Considering that women, who are over half the population, have been at risk of being treated using data based on the male model—and thus not necessarily based on evidence relevant to female physiological variables—there is an especially important need to move gender-based research to the point of need. Librarians are uniquely positioned to help promote the incorporation of current research into practice. Librarians, using entrepreneurial approaches, can invest their time, resources, expertise, and services for long-term social value—becoming social entrepreneurs in the process.

“Getting the word out” can be a powerful “contagion” for creating an information “epidemic” (Seltman, 2004). Librarians are in especially superior positions to do this because in all areas of their jobs the central mission is to provide access to information in the most expeditious ways possible—literally, to get the word out. To do this librarians collect, manage, organize, promote, share, and distribute information and knowledge. Reference, collection development, bibliographic instruction, and cataloging activities all are opportunities to accomplish their mission. Access

to relevant print and online resources, including blogs, along with knowledge about search strategies and relevant databases provides the librarians numerous opportunities to spread the word. GenderBiology.net, a gateway to news and resources about gender biology and gender medicine for healthcare consumers and professionals and information professionals, is this librarian's contribution to social entrepreneurship.

Whether as an innovator or connector or change agent or social entrepreneur, librarians play an important role in getting this gender-specific biomedical research information translated to real world application. No action is too small. We can incorporate new knowledge into most any librarian application. But when a moment seems appropriate, when the moment happens that a connection can be made between your activities of daily living to this knowledge, use the power of word of mouth. Small actions *can* lead to great change. We *can* make a difference. We can find ourselves changing the world one librarian at a time.

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