

**Evaluating the Social Factors that Influence
Government Funding of Women's Health Research**

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Olivia Mergler

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

Advisor

Rider W. Foley, Department of Engineering and Society

The State of the Women's Health Movement

In the 1960's and 1970's female activists initiated the women's health movement, demanding "improved health care for all women and an end to sexism in the health system" (Nichols, 2000). During that time, the movement largely took on goals related to transforming women's reproductive rights to change childbirth practices and increase legal abortion access. Although these movements initiated a powerful change in medicine, over the past sixty years, the women's health movement has made rather slow progress. Due to historical biases, underrepresentation of females in medical research, poor funding, and limited awareness of the diseases that affect women differently than men, women's health continues to be undervalued and understudied.

Despite efforts to expand women's health research through increased funding allocations and the establishment of organizations such as the National Institutes of Health (NIH) Office of Research on Women's Health (ORWH), there still exists a general unawareness and underfunding of research towards women's health conditions that affect women beyond reproduction (Bustreo et al., 2012). For example, in six leading women's health journals in 2020, reproductive health made up 49% of the research (Hallam et al., 2022). Conversely, noncommunicable diseases, such as cancer, mental illness, substance abuse, and cardiovascular disease made up only 31% of research (Hallam et al., 2022). Noncommunicable diseases as such pose unique risks and presentations in women compared to men and are the leading causes of death and disability for women, warranting greater prominence in women's health research (Hallam et al., 2022). Additionally, although menopause affects all women for up to 40% of their lives, the biological and environmental factors that influence the onset, symptoms, and comorbidities of menopause are still largely unknown. Even with these gaps, in 2019, only 28

NIH grant proposal titles included “menopause”, whereas over 300 included “pregnancy” (Aninye et al., 2021).

These disparities in research have created a poor understanding of many fundamental women’s health principles outside of this narrow scope, making medicine less effective, and even harmful for women (Cleghorn, 2021). For example, heart disease is the leading cause of death in women, causing one in five female deaths (CDC, 2024). Despite women having worse outcomes from cardiovascular disease than men, both patients and clinicians have limited awareness of the unique risks and symptoms of heart disease in women, and women are 35% less likely to receive preventative care for heart disease than men (Johns Hopkins Medicine, n.d.). Similarly, as a result of decades of research pertaining to risk factors of developing drugs with no female representation, women continue to experience adverse drug reactions nearly twice as often as men (NIH, n.d.; Zucker & Prendergast, 2020).

Allocations for government funded research are influenced by factors including the awareness and advocacy of specific conditions. This paper aims to investigate the social and systemic factors that contribute to the disproportionate ORWH funding of women’s health diseases relative to their prevalence and associated risks.

Challenges and Progress of the Women’s Health Movement

Medicine has instilled a distorted valuation of women’s health, prioritizing reproductive health over the most prevalent/burdensome diseases for women (Hallam et al., 2022).

Foundational understanding of women’s health, dating back to Ancient Greece associates any female-specific conditions to the value female’s held in society: their ability to reproduce (Cleghorn, 2022). This created a lasting focus on women’s health to support fertility and

pregnancy, limiting interest in conditions that affect women outside of their reproductive years. Furthermore, for centuries, medical attitudes towards women's health dismissed women's complaints of pain and illness, distilling their concerns to hysteria. As a result, medical professionals focused on the idea that emotional factors, rather than biological factors, were responsible for women's health issues, perpetuating a skewed perspective of sex-based differences in health (Cleghorn, 2021).

By the 1960's and 1970's, advocacy for reproductive rights initiated a change that empowered women to assert autonomy over their health. Large strides were made in the following years as concerns for the potential of sex-based differences in medicine such as heart health, AIDS, and osteoporosis rose (Nichols, 2000). However, in 1977, the Food and Drug Administration (FDA) limited the inclusion of women of childbearing age in drug trials due to potential risks to fertility (NIH, n.d.). This restriction perpetuated generalizations in medicine that significantly delayed the understanding of many biological differences between sexes. These assumptions continue to be used as a basis for medicine today.

Despite these historically driven limitations, government changes in the valuation of women's health over the last four decades have shaped the modern efforts to prioritize and recognize the importance of women's health research. Since its establishment in 1990, the ORWH has facilitated women's health research with the intent to identify and understand sex-based differences in health and disease. Within the first three years of their initiation, the NIH Revitalization Act of 1993 was executed, creating federal laws mandating the inclusion of women and minorities in clinical studies (NIH, n.d.). These guidelines became instrumental in improving female representation, and thus, the understanding of sex-based differences in response and risks to treatments. By 2016, the ORWH led the development of the NIH Policy on

Sex as a Biological Variable, emphasizing the need for the influence of sex on health and disease to be considered in both clinical and preclinical research (NIH, n.d.). Most recently, in November 2023, President Biden released the first-ever White House Initiative on Women's Health Research, collaborating with heads of the ORWH (The White House, 2023). This work highlights continued initiatives to improve diagnostic and treatment strategies for understudied women's health conditions including cardiovascular disease, Alzheimer's, autoimmune disorders, mental health conditions, and conditions specific to women such as endometriosis and fibroids through promotion of research for these conditions and a \$12 billion NIH research fund (The White House, 2023).

Research Funding Influences

The allocation of government funded research budgets is strongly influenced by public disease advocacy during periods of budget growth, as seen in the NIH since 2015 (Congressional Research Service, 2023). Rachel Kahn Best's study, *Common Enemies: Disease Campaigns in America*, delineates the complex factors that are predictive of widespread disease advocacy through analysis of historical trends in disease campaign mobilization (Best, 2019). Through her investigation, she found three primary factors of successful disease campaigns: 1) the prevention of a disease has the potential/perception of a universal benefit or benefit to a worthy group (universal or valorized beneficiaries), 2) the advocacy campaign maintains a specific disease target (narrow causes), and 3) addressing the disease raises minimal controversy (avoiding controversy). This outline provides a framework to assess how these influences have shaped the ORWH research funding allocation.

Universal or Valorized Beneficiaries

Best poses two different campaign models that were popularized in the 20th century to generate mass support for disease advocacy. First, Charitable Crusades, which relied upon mass participation in campaigns due to the perceived universal threat of infectious disease.

Alternatively, Disease Constituencies, which rely upon the leadership of valorized patients, typically of rare chronic diseases, for the campaign success.

Breast cancer is the most popular example of a highly mobilized women's health disease campaign. Every October, millions of women participate in Breast Cancer Awareness Month, promoting education and prevention of the disease (WHO, 2022). Breast cancer spans both the Charitable Crusades and Disease Constituencies model, as one in eight women will develop breast cancer, and patients are widely public in their advocacy (CDC, 2023). As a result of the publicity of the disease and the promising groundwork of the disease research, breast cancer has consistently been a top research focus of the ORWH since its inception (NIH, 2021).

However, this degree of awareness and publicity is not widespread in women's health diseases. Due to the relatively new and limited understanding of the sex-based differences in disease, many women are still not aware of the diseases that pose unique risks (Cleveland Clinic, 2022). For example, despite 1 in 5 women between the ages of 55 and 75 having a stroke, only 11% of women are aware of the female-specific stroke risks and stroke research received less than 1% of ORWH funding in 2019 (Kraft, 2015; NIH, 2021).

Narrow Causes

Best assesses that successful disease campaigns also often rely upon a narrow scope, particularly a single disease. Maintaining a narrow focus on a single disease increases the likelihood of consensus on disease support, motivating greater involvement.

Many national disease advocacy groups have created separate campaigns for women's health implications specifically. For example, the American Heart Association created the Go Red for Women campaign to raise awareness for cardiovascular disease in women (*About Us*, n.d.). This organization works closely with the NIH to ensure their budget addresses their research priorities, reflected through the 5.9% of the NIH budget allocated to heart disease (NIH, 2021). However, due to the limited awareness of the diseases that affect women uniquely, many specific disease campaigns are not well developed. For example, the Respiratory Health Association's women's health campaign seeks to address asthma, COPD, lung cancer, pulmonary fibrosis, tobacco control *and* air quality (Respiratory Health Association, 2023). In 2019, lung disease received less than half of the amount of ORWH funding that HIV/AIDS research received, despite causing 100 times greater deaths in women (NIH, 2021; World Health Organization, 2023).

Avoiding Controversy

To obtain widespread support, disease campaigns rely upon uncontroversial diseases and solution paths. Disease campaigns are more difficult to mobilize if they address preventable, infectious, or mental illnesses, or challenge systemic beliefs and demand social change.

It is evident that many women's health problems stimulate fierce political discussion, particularly related to abortion and contraception limiting the government involvement in its

research funding (Harris, 2013). However, this politicalization does not span the entirety of the women's health agenda. Women's health diseases such as osteoarthritis, Alzheimer's, and heart disease generate minimal political discussion, reducing their public controversy. However, they continue to pose a significant challenge in medical research in that they disrupt the basis on which medicine is founded. By introducing sex-based differences in diseases that were not initially associated with women's health, decades of research, diagnostics, and treatment options are called into question. Investigating the role of genetic, hormonal, and lifestyle factors that differ between men and women requires significant reevaluation of the assumptions embedded in our fundamental understandings of health (Liu & Mager, 2016).

Research Question

It is evident that factors beyond disease burden are used to inform the ORWH budget allocation. This prompts the question, what factors pertaining to disease advocacy influence the government funding decisions for women's health research? This investigation will be done through the lens of Rachel Kahn Best's Common Enemies to investigate the factors that contribute to successful disease advocacy and funding (Best, 2019).

Methods

This research aimed to understand the relationship between the government funding of women's health research and the respective public perceptions of women's health conditions. A review of the ORWH Biennial Reports of the Advisory Committee on Research on Women's Health for the fiscal years 2015 to 2020 were used as a metric for the government funding allocated specifically for women's health conditions (budget only reported for years 2015-2019)

(NIH, 2017, 2019, 2021). The World Health Organization's (WHO) global health estimate was used as a standard metric for disease burden (WHO, 2023). In particular, disability associated life years per 100,000 people (DALYP) for American women of all ages was used as the burden quantification. This quantification measures years lost due to premature death or disability, enabling analysis of non-fatal diseases such as mental health. To understand the relationship between disease funding and prevalence, a ratio of the percent of annual ORWH funding and the relative burden as a percent of the sum of all disease burdens for each disease was calculated, termed the Funding to Prevalence Ratio (FPR). For example, breast cancer received 23.2% of the ORWH funding in 2019, and accounted for 3.6% of the total DALYP, therefore it received a FPR of 6.4 in 2019. Disease categorizations that poorly overlapped between the two databases were excluded from analysis to ensure funding was accurately representative of the associated burden.

The top three overfunded (highest FPR) and top three underfunded diseases (lowest FPR) of the remaining disease categories were used for analysis. This analysis was followed by thematic coding by reporting the number of times terms related to the selected disease categories were mentioned in each report. This measure was used to better understand the focus of each report and assess alignment with funding allocations. Lastly, the selected disease categories were further evaluated for their alignment with Best's factors of disease advocacy through the disease discussion and characterization in the ORWH reports, such as the affected populations or underlying causes the ORWH associated with each disease.

Results

The resulting over and underfunded disease categories closely aligned with Best's factors of successful disease advocacy. From this analysis, the funding influence of universal/valorized

beneficiaries was most evident in disease categories that require routine screenings like breast and cervical cancer, and diseases that affect predominantly young women such as HIV/AIDS. The inverse effect was also observed, where diseases associated with beneficiaries that have been stigmatized, such those affected by mental health, or older patients, such as those who experience strokes, received disproportionately less funding. The influence of a narrow cause was apparent when contrasting the relative funding of disease categories that focus on a single disease state, such as breast cancer, where funding is favored, against broader categories, such as hepatobiliary disease. Lastly, uncontroversial diseases were hallmarked by diseases that affect only or predominantly women, like cervical cancer and breast cancer. Diseases that affect women and men differently, such as strokes, can be perceived with greater controversy as they require altered assumptions of traditional medical practices.

The resulting range of FPRs reflects starkly over and underfunded diseases, highlighting limited association between disease funding and DALYP (Table 1). For example, despite strokes causing over 10 times greater DALYP than cervical cancer, strokes received less than 1/5 of the funding of cervical cancer in 2019. Most notably, anxiety and depression caused 35 times greater DALYP than HIV/AIDS but received 1/7 of the funding in 2019. This lack of association indicates alternate factors that influence the budget development which will be further discussed through the Common Enemies framework.

Table 1: Average FPR for the top three overfunded and underfunded diseases for 2015-2019.

	Condition	FPR
<i>Overfunded</i>	HIV/AIDS	24.3
	Breast Cancer	6.5
	Cervical Cancer	5.3
<i>Underfunded</i>	Stroke	0.13
	Hepatobiliary Diseases	0.021
	Anxiety and Depression	0.012

Thematic coding to quantify the initiatives discussed within the reports was not entirely representative of funding discrepancies (Figure 1). Breast cancer and HIV were discussed abundantly. For example, HIV was mentioned over 500 times in both the 2015-2016 and 2017-2018 reports. Similarly, breast cancer was consistently referenced in cancer discussions, making up at least 30% of all mentions of cancer throughout each report. However, in 2015-16 and 2017-18, strokes and depression were discussed to a similar extent as cervical cancer, minimizing distinct differences in disease mentions relative to the FPR. These trends indicate a recognition of disease severity and necessity to prioritize their research and prevention, although limited funding is actively allocated towards these underfunded diseases.

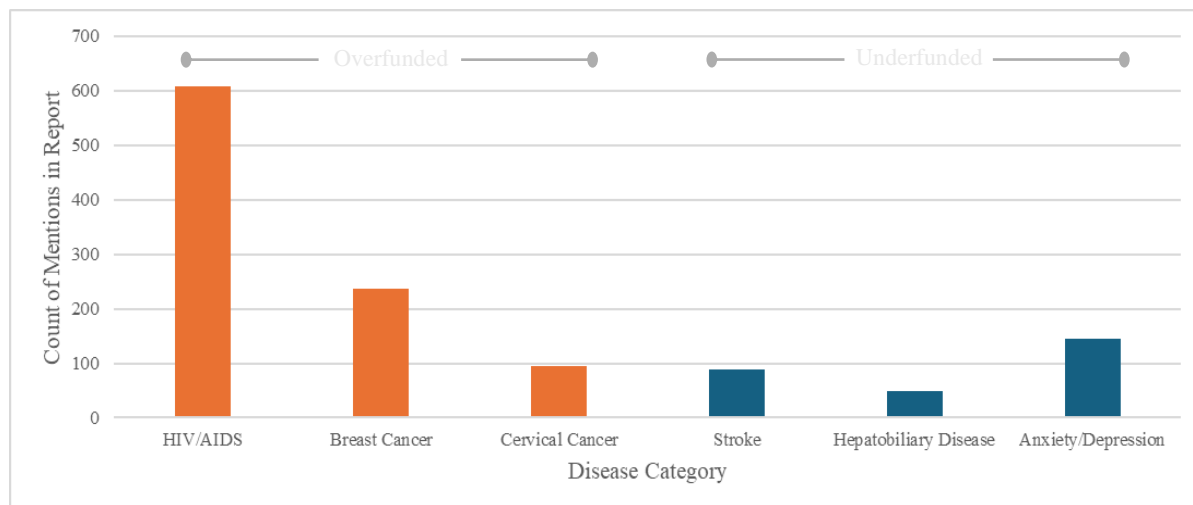


Figure 1: Representative thematic coding quantification from 2017-2018 ORWH report. Search terms to quantify the mentions of each conditions were as follows: HIV/AIDS: HIV, AIDS; Breast cancer: breast cancer; Cervical cancer: cervi; Hepatobiliary disease: heapt, bili, liver; Stroke: stroke; Anxiety/Depression: anxiety, depress.

Universal or Valorized Beneficiaries

The perceived widespread threat of diseases can be associated with the awareness the conditions receive. In the United States, breast cancer accounts for nearly 1 in 3 of all new female cancers per year, with a 13% lifetime risk of females being diagnosed with breast cancer (American Cancer Society, 2024). Women are also encouraged to schedule annual mammograms as well as perform routine self-checks for breast cancer screening. These persistent reminders embedded in women’s healthcare serve to ensure that women are aware that breast cancer is a real and likely threat. Although cervical cancer affects a much smaller population of American women, killing 1/10 the number of women annually as breast cancer, the perceived threat continues to be high. This can similarly be attributed to routine pap smears used as a cervical cancer screening.

The perceived age groups that these conditions affect can also serve as a predictor of a valorized patient population. For example, the NIH explains that, “in women ages 20 to 39 years,

breast cancer and cervical cancer are the first and second leading causes of cancer deaths” (NIH, 2017, p66). Alternatively, strokes are commonly associated with elderly populations as over 75% of strokes occur over the age of 65 (Kelly-Hayes, 2010). Due to inherent ageism in the medical field, developing medicine to treat younger populations is much more attractive than spending resources on elderly patients (American Medical Association, 2022).

Furthermore, according to Best, stigma associated with patient groups also influences disease support, however this theme was more convoluted within this data. Preventable diseases such as hepatobiliary disease are less likely to be supported due to the perceived self-infliction of the condition (Best, 2019). Liver disease is particularly stigmatized due to its association with alcohol and drug abuse. However, 93% of cervical cancers are also preventable with human papillomavirus (HPV) vaccination (CDC, 2020). Similarly, HIV is also highly preventable through diligent use of sexual protection. These contradictions highlight the power both of alternate influencing factors, as well as historic efforts to reduce stigma, particularly in the case of HIV/AIDS.

Anxiety and depression pose an interesting case in that they affect predominantly younger populations, with 75% of mental health problems established by age 24, making it appealing as a valorized population (Mental Health Foundation, n.d.). However, the stigma associated with mental health, of which is especially heightened due to distrust of the concerns of younger populations, seemingly outweighs this valor (WHO, 2021).

Narrow Cause

Each of the overfunded disease categories covered a single disease, creating a concise focus on disease campaigns and funding efforts. Externally, these categories have been pivotal in

establishing advocacy groups. Breast cancer is hallmarked by the National Breast Cancer Foundation pink ribbon, and cervical cancer advocacy is led through the National Cervical Cancer Coalition. Within the NIH, both categories receive independent initiatives, such as the TAILORx breast cancer clinical trial, or extensive research on HPV vaccinations for cervical cancer prevention (NIH, 2019). Within the infectious disease category, HIV/AIDS similarly receives extensive focused attention, enabling highly specific initiatives such as exploring the intersection of alcohol misuse and HIV exposure in young women (NIH, 2019).

Unlike the overfunded diseases, hepatobiliary diseases encompass a broad range of diseases that affect both the liver and biliary system including chronic liver disease, liver cirrhosis, and viral hepatitis. The few described initiatives that are targeted for liver disease focus on broader research areas such as sex influence in liver disease and understanding metabolic pathways that influence fat deposition (NIH, 2019). These research targets highlight the high-level understanding of the systems still necessary to further accomplish more specific research.

Avoiding Controversy

Beyond the limited stigma previously discussed, controversy within the assessed women's health research areas is largely due to contradictions towards previous health understandings based upon male-dominated assumptions. For some overfunded diseases like breast and cervical cancer, these contradictions are limited. Although basic understandings of cancer and cancer therapies are based within male health, due to breast and cervical cancers predominantly affecting women, they offer unique opportunities to pioneer female-specific investigations. As a result, much of this work is additive to basic understandings, rather than requiring reassessment of prior assumptions.

Alternatively, each of the underfunded disease categories affect both men and women, and, importantly, affect them differently. For example, “being a premenopausal woman... is associated with increased histologic severity of hepatocyte injury and inflammation” with non-alcoholic fatty liver disease (NIH, 2019, p216). Similarly, young girls have higher rates of anxiety than young boys, and after puberty, have higher rates of anxiety and depression than men (NIH, 2019). Women also have poorer functional outcomes after stroke, and experience higher risks of stroke during pregnancy (NIH, 2017). Each of these differences are hypothesized to be associated with hormonal differences, a fundamental discrepancy historically neglected in research (NIH, 2017, 2019). This is both due to poor awareness of the disparities, as well as limited development of resources to study sex-based differences. In the case of liver disease, the NIH explains that “a robust animal model for studying the disease has been sorely lacking, in particular because in the best mouse model females do not develop human-like disease under usual laboratory housing conditions” (NIH, 2019, p215). Therefore, to better understand and develop solutions to these health disparities, improved models and analytical methods must be integrated into research, complicating traditional methods, and potentially contradicting basic research assumptions.

Discussion

This research used Best’s analysis of factors influencing disease campaign success in Common Enemies to understand the relationships between women’s health disease characteristics and the respective ORWH funding. From this analysis, it is evident that disease characterization such as association with a stigmatized patient group, unfocused disease categorization, and disease misalignment with traditional medical assumptions perpetuated the

underfunding of the disease. This framework informed a method to deconstruct the diseases to understand their public perception. By relating this framework to the ORWH funding, this study confirms the apparent influences of public perception on the distribution of government funded women's health research. Many of the current assessments of the state of women's health research establish associations with reproduction as a primary factor in research priorities (Hallam et al., 2022). Best's framework opens a more comprehensive exploration of the broader factors that contribute to overall disease advocacy, which interestingly and appropriately do ultimately converge on a preference for reproductive-focused conditions. However, encouragingly, the influence of disease advocacy underscores the power of public support in shaping the research landscape. Recent strides, such as the White House Initiative on Women's Health Research, demonstrate public recognition of the need for research priority changes, and opens significant opportunities for advocacy groups to use their platforms to shape the new budget.

This study is limited primarily due to the narrow scope of the diseases assessed and the compilation of two independent data sets. This study only analyzed the disease burdens for American women, however, some NIH research efforts establish global humanitarian aid. By accounting for global health burdens, conditions such as infectious diseases would have much higher respective burdens. Therefore, it is necessary to further investigate this approach using a global burden quantification to better appreciate the NIH global health priorities.

Furthermore, due to different categorization between the ORWH funding data and the WHO burden data, some inconsistencies arose when merging the datasets. As a result, broader disease categories defined by ORWH, such as hepatobiliary diseases, were associated with burdens of multiple WHO disease groups, such as gallbladder/biliary diseases and liver cirrhosis.

Additionally, some research areas such as maternal health that include general pregnancy research were not well reflected by the burden quantifications, which only quantified maternal conditions that cause maternal injury or death. Therefore, future efforts should be made to identify or create a dataset that better aligns with disease definitions assumed by the ORWH.

As someone who seeks to continue biomedical research within women's health, this research is formative in understanding the future hurdles in my research ambitions. To continue to explore fundamental female biomechanics in disease states like pelvic organ prolapse, a large shift is necessary in channeling awareness and advocacy towards the condition. Particularly, this has revealed the framing necessary to gain support of my future research, such as emphasizing the widespread threat of the disease. It has also inspired me to use my emerging background in women's health beyond a purely engineering focus. Although research is important, efforts towards advocacy and campaign development can have a much broader and lasting impact on the field.

Conclusion

This work highlights the role of disease perception and advocacy on research funding. Quantitative analyses were used to identify discrepancies of disease burden and research funding, highlighting several disease areas that necessitate greater research priorities. Although complete reallocation of the ORWH budget to minimize the range of FPRs would halt valuable ongoing work in overfunded research areas, efforts can be made to proactively alter the budget making process during periods of budget growth. Within the NIH, this can be achieved by more strongly weighing disease burden over disease lobbying. However, until disease lobbying becomes less effective in NIH budget allocations, this study also offers valuable perspective in

how to frame future disease campaigns to influence budget formation and reduce funding disparities. The Common Enemies framework offers a rather open outline of the important campaign criteria, highlighting the potential flexibility of disease characterization to strengthen its advocacy. It is evident that by capitalizing on desirable disease factors, such as the universal threat and specificity of cervical cancer, undesirable factors can be overlooked, like the preventability of cervical cancer, to create an overall successful campaign. From both Best's work as well as the present study, it is evident that public support of disease campaigns are influential factors in the decision-making process of government funding allocation, highlighting the power social efforts have in medical progress. By better understanding the ways in which private groups can effectively advocate for desired research areas, funding can be redistributed to better reflect healthcare needs.

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