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National Academies to NIH: Boost Studies To Better Treat Women's Chronic Diseases

By Jane Anderson

NIH and other federal research agencies need to enhance their research efforts to better understand chronic conditions in women to close “significant gaps” in knowledge about how those conditions impact diagnosis, treatment and prevention, a report from the National Academies of Sciences, Engineering, and Medicine found.^[1]

The report from the Committee on a Framework for the Consideration of Chronic Debilitating Conditions in Women identified challenges in care provided for chronic conditions that are specific to women, predominantly impact women, or affect them differently, such as endometriosis, pelvic floor disorders, migraines, and chronic fatigue syndrome (CFS). The authors recommended that NIH and other federal agencies pursue research in areas with specific knowledge gaps.

“Imprecise diagnostic criteria, inadequate assessment of the burden of conditions impacting women, and lack of representation of female-specific conditions on national surveys were among the challenges identified in crafting a new framework,” the report said. “The extensive review of the literature underscored the social and economic contributors to health and well-being of women over their life span that have not been robustly integrated into studies focused on topics such as pathophysiology, access to care, and disease management.”

Women generally outlive men, the authors stated, but prior research has shown that they spend approximately nine more years with suboptimal physical, social, and psychological well-being. In addition, 47% of conditions affect women disproportionately, 4% affect them differently and 5% are exclusive to them, according to the report.

“Clearly, the toll of chronic conditions on the lives of women is likely underestimated, given such factors as shortfalls in data and an underrepresentation of women in clinical research studies,” the report said. “Women comprise 50.4% of the U.S. population and are the primary caregivers of others in their families, and often significant contributors to the financial security of their loved ones. At times, their own health needs thus become secondary to those for whom they are providing care, so they minimize their symptoms and delay necessary interventions that can resolve the impacts of their medical conditions early in their life course.”

Ultimately, the committee said it reconsidered its original approach to the report that assessed chronic diseases in women and instead chose what it called “a life course perspective,” which offered an opportunity to consider women's chronic diseases within all structural, social, and cultural contexts.

The panel identified four specific gaps in knowledge about how chronic conditions affect women:

- Uncertainty related to the actual burden that specific chronic conditions have on women;
 - Absence of pertinent data on female-specific conditions in national databases;
 - Lack of a deep understanding of the etiology of specific chronic conditions and the impact of reproductive
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milestones on those chronic conditions; and

- Impact of structural and social determinants, early-life experiences, and lifestyle behaviors in women’s overall health.

The report urged NIH and other relevant agencies to fund research to fill those gaps and listed 10 categories of recommendations that would accomplish the goal.

Impact of Chronic Conditions

Several challenges arise in quantifying and measuring the impact of chronic conditions in women: the conditions can be difficult to diagnose, have wide variability in diagnostic approaches, have an unknown etiology or have high diagnostic misclassification resulting from their association with multimorbidity and similarities to other conditions, the report said.

In addition, the quality of life in women living with chronic conditions has been challenging to measure and economic burden is another measure for which little knowledge exists other than that chronic conditions in women contribute to substantial health care costs and have a significant effect on a woman’s productivity, the report said.

“Limited data hinders an in-depth understanding of the burden that chronic conditions have on women,” the authors wrote. “Many chronic conditions are understudied, and measurement and diagnostic challenges lead to underreporting and inaccurate findings.”

Based on these findings, the committee urged federal support for research to improve estimates of the impact of chronic conditions on women. Specifically, the report said, research is needed to more accurately diagnose and reduce misclassification of female-specific and gynecologic conditions (e.g., endometriosis, vulvodynia); diagnose chronic conditions that predominantly impact or affect women differently (e.g., chronic pain, myalgic encephalomyelitis/CFS (ME/CFS) and autoimmune diseases); characterize differences in chronic condition presentation by gender, race and ethnicity, and various structural and social determinants that these women experience or are affected by; and assess the economic impact of chronic conditions in women (both direct and indirect costs) and quality of life.

In addition, many of the surveillance systems for chronic conditions do not capture or track female-specific and gynecologic conditions, the report said. To improve data collection on these chronic conditions—along with those that predominantly impact or affect women differently—federal research agencies should support national surveillance and population-based studies to expand data collection activities to include female-specific and gynecologic conditions and female-predominant conditions not currently included, the report recommended.

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