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Gender perspective and determinants associated with the linkage women-informal or primary care

Perspectiva de género y determinantes asociados al vínculo mujer-cuidado informal o primario

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Abstract:

The primary caregiver is a fundamental part of the health-disease process of the patient with a disabling, chronic, or transitory illness. The participation of women in care is greater compared to men. It happens in various studies of informal caregivers of multiple diseases or disabling conditions. Feminist economics, from the perspective of care economy, points out the importance of considering the determining role of gender relations to explain the concentration of women in care activities and the minimal or less favorable participation in the work market. This narrative review aims to recognize some sociodemographic characteristics that allow the problem to be analyzed from a gender perspective, especially to make visible the determinants associated with the link between women and primary or informal care. The recent approval of the national care system is a small advance in the challenge that care for primary caregivers entails. However, it is necessary to generate public policies that contribute to the well-being of caregivers, starting by the recognition of their needs in different areas. It is relevant to consider social changes, population aging, the increase in the number of people who are dependent due to age or disability, demographic changes, and new family, work and cultural models.

Keywords:

Informal care, gender perspective, sociocultural determinant, women, care.

Resumen:

El cuidador primario es una parte fundamental en el proceso de salud-enfermedad del paciente con alguna enfermedad incapacitante, crónica o transitoria. La participación de las mujeres en el cuidado es mayor en comparación con los hombres, como lo demuestran diversos estudios sobre cuidadores informales de múltiples enfermedades o condiciones incapacitantes. La economía feminista, desde la perspectiva de la economía del cuidado, señala la importancia de considerar el rol determinante de las relaciones de género para explicar la concentración de las mujeres en las actividades de cuidado y su participación mínima o menos favorable en el mercado laboral. El objetivo de esta revisión narrativa es reconocer algunas características sociodemográficas que permitan analizar la problemática desde una perspectiva de género, sobre todo para visibilizar los determinantes asociados al vínculo mujer-cuidado primario o informal. La reciente aprobación del sistema nacional de cuidados representa un pequeño avance en el desafío que conlleva la atención para los cuidadores primarios. Sin embargo, es necesario generar políticas públicas que contribuyan al bienestar de las personas cuidadoras, partiendo desde el reconocimiento de sus necesidades en los distintos ámbitos. Es importante considerar los cambios sociales, el envejecimiento poblacional, el aumento del número de personas dependientes, ya sea por edad o discapacidad, los cambios demográficos, y los nuevos modelos familiares, laborales y culturales.

Palabras Clave:

Cuidado informal, perspectiva de género, determinante sociocultural, mujer, cuidado.

INTRODUCTION

Despite the special interest shown by the Ministry of Health in our country to promote the integration of gender perspective through programs and research in health system policies and actions, gender biases persist in healthcare practice.[1] Gender bias, according to the American Medical Women's Association, is the difference in the treatment of individuals of both sexes presenting the same clinical diagnosis, which can result in positive, negative, or neutral consequences for their health.[2]

Every day, women face discriminatory acts simply because of their gender. This reality is observed in various areas, and although it may seem like a recurring issue, discrimination against women in Mexico remains a constant reality. These situations occur regularly, are evident in our society, and manifest in various forms.[3]

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Gender bias in healing treatment is influenced by gender bias in diagnosis, as the likelihood of receiving treatment is nearly nonexistent if the individual is excluded from the diagnostic process for any reason or decreases if appropriate tests are not conducted during diagnosis. Without a diagnosis, only symptomatic treatment or overprescription of psychotropic drugs is likely to be implemented.[4] The presence of gender disparities in the manifestation of illnesses, regardless of how men and women report their discomfort, may be contributing to delays and incorrect diagnoses.[5]

Understanding informal care incorporates a gender perspective, as this theoretical approach allows consideration of other elements that add to the inherent challenges of caregiving, emphasizing vulnerability to health and quality of life among primary caregivers.[1]

In Mexico, there has been an increase in male involvement in caregiving, attributed not to a generational shift but rather to sociodemographic and familial factors. In urban settings, men tend to spend more time on household chores, especially when their wives are employed. As age increases, so does the time devoted to domestic tasks, and men who devote more hours to household chores also spend more time caring for their children.[6] However, it is crucial to verify their current participation, identify gender inequality practices in the distribution of informal care, and to recognize the health and well-being implications for women caregivers.

Gender inequality in caregiving manifests in the distribution and intensity of tasks, as well as in the evident repercussions on caregivers' lives, especially on the physical and mental health of women who assume this role.[7]

In recent decades, profound social changes have occurred, largely due to population aging, an increase in the number of dependents due to age or disability, demographic changes, and new family, work, and cultural models. These changes have led to an increased demand for care, while the proportion of women available for full-time caregivers has decreased[3], leading to men's participation as primary caregivers, especially in roles as spouses and children.[8]

This narrative review reflects on the gender perspective and sociocultural determinants associated with the woman-care link. It is a topic of complex interest that seeks to raise awareness among readers, especially concerning the pursuit of gender equity in activity distribution. The mere definition of equity promotes discussions and personal interpretations based on convenience. The topic is addressed in subthemes to understand it sequentially and in a focused.

PRIMARY OR INFORMAL CAREGIVERS

The "primary caregiver or informal caregiver" concept applies to the person who primarily assumes the responsibility of caring for and attending to an individual who requires assistance due to illness, disability, old age, or other forms of dependency. Generally, they lack training to perform the activities inherent to caregiving and do not receive economic compensation. This figure can be a family member, a close friend, or a professional caregiver.[9]

The primary caregiver offers constant elementary assistance and typically forms an emotional bond with the patient. It implies changing behaviors and lifestyles to take responsibility for the care and well-being of the sick person.[10]

In many cases, these caregivers face the situation without having the necessary knowledge, which can impact their health significantly. Some of them emphasize the importance of acquiring skills to provide essential care. The lack of proficiency in caregiving can affect both the patient's and the caregiver's health.[11]

CHARACTERIZATION OF THE PRIMARY OR INFORMAL CAREGIVER

Studies related to informal caregiving report the characteristics of the primary caregiver for different illnesses, mostly concurring that women undertake this role. Below are some examples:

According to a 2019 study conducted in Ecuador 73.3% of primary caregivers of oncological patients were women, among whom 63.3% were married and 53.3% had a high school education. Primary caregivers of cancer patients: A participation rate of 73.3% of women is reported, with 63.3% being married and 53.3% having a high school education.[12]

According to a 2019 study conducted in Mexico, in the case of primary caregivers of pediatric patients with cancer, 94% are women, with 91% being the mothers of the patients. 43% are married, and 31% are in a common-law marriage. 55% are homemakers, and 32% are unemployed. Regarding education, 28% have completed high school education, and 29% have completed higher education. Ages range from 18 to 59 years old. 68% of caregivers have not received psychological support.[13]

According to the findings of a 2020 study conducted in Mexico, in primary caregivers of patients with chronic kidney disease, 81% are women, ranging from 15 to 80 years old. 50% are spouses, and 15.4% are parents. Regarding the duration of caregiving, 27% have been caregivers for 1 to 3 years, 19% for 3 to 5 years, 19% for 5 to 10 years, and 19% for over 10 years. From these 54% mention receiving support from others in patient care.[14]

According to the findings of a 2020 study conducted in Mexico, with primary caregivers of older adults: 69.7% are women, with an average age of 52 years. 64% are married, and 38.6% have primary education. 41% experience intense caregiver burden.[15]

According to the data obtained in Mexico in 2017 from a population of primary caregivers of children with intellectual disabilities, 86% were women aged between 24 and 53 years.[16]

Another 2019 study was conducted in Mexico, but with a population of primary caregivers for disabled girls and boys, 100% were women, with average ages between 30 and 40 years old, and 48% had high school education. All of them engaged in domestic activities.[17]

In 2020, a study conducted in Mexico on a population of primary caregivers of patients with attention deficit hyperactivity disorder found the following: Approximately 80% are women and mothers. Close to 50% declare being the sole responsible for the upbringing of the child. 15.8% have a high school education, and 50% are engaged in domestic work. Only 19.2% have formal employment, and 60% do not have health insurance.[18] In 2023, a study conducted in Ecuador on a population of primary caregivers of patients with physical disabilities found that males predominate, with ages ranging from 40 to 64 years. The majority dedicate more than 37 months to caregiving, and 43% do so 24 hours a day.[19]

These data highlight the prevalence of the primary caregiver role among women and the various characteristics associated with this role in different healthcare contexts. Another important aspect to consider is why the person chooses to be a primary caregiver, such as cultural heritage, feelings of obligation to care, and delegation of caregiving tasks.[20]

OVERLOAD OF PRIMARY OR INFORMAL CAREGIVER

The caregiver burden syndrome is characterized by the presence of stress, anxiety, depression, irritability, insomnia, difficulty concentrating, apathy, loss of appetite, headaches, or substance abuse, among others. These individuals feel guilty and set aside their leisure and recreational activities, as well as their friends, to fully dedicate themselves to caregiving tasks; they also express sadness and environmental tension, are unable to relax, and may experience social isolation and feelings of loneliness.[21]

The caregiver burden manifests in various ways, such as neglect of one's own health, interruption of life and social projects, family deterioration, anxiety, or frustration due to technical unfamiliarity in caregiving. Women bear the highest burden of care, contributing to increased gender inequalities in health and society overall.[22-24] The burden perceived by women caregivers is closely related to the level of dependency of the care recipient, the hours of caregiving, social support, and mental health variables such as anxiety. In women caregivers, the perception of higher social support is associated with a lower perceived burden.[24] Other factors that may impact the caregiver burden include the patient's family dynamics, the amount of time spent caregiving, the patient's health status, and the living situation, among others.[15,25]

SOCIAL AND CULTURAL DETERMINANTS OF CARE

The detrimental impact on the health of primary caregivers is closely related to sociocultural variables, some of which explicitly include gender.[26] It is also associated with the caregiving years, the assistance availability in caregiving, the patient's needs arising from the dependency level, and the caregiver's age.[27]

The act of caregiving has traditionally been assigned to women, along with the feeling of obligation to act as caregivers, stemming from socially and culturally established gender roles, leading them to perform as such. The act of caregiving is perceived as something natural, a moral obligation, and a responsibility assumed as feminine. They also provide support to other women in caregiving.[28]

There are significant gender inequalities in the distribution of caregiving and a particular sociocultural positioning between men and women related to caregiving, determined by gender social roles. Women tend to internalize caregiving as a personal competence, assuming the total burden without delegating responsibilities and risking their self-care.[7,29]

Among the sociocultural determinants, the role played by women within the family structure stands out. Social roles are integrated into our upbringing and personal development, and the family is the first institution where we develop. Gender-based differentiation of activities is widespread, even when it is not explicitly stated; certain activities are traditionally associated with specific genders, reinforcing societal expectations. [30]

Economic participation is another social determinant. Often, women are expected to leave their jobs to dedicate themselves full-time to caregiving, justified by the argument that they have lower economic incomes and limited development opportunities compared to their male partners. This situation arises because the overload of responsibilities negatively affects their availability for paid work.[7,31,32]

The socioeconomic level plays a crucial role in the dynamics of caregiving. In households with higher economic resources, there is the possibility of using market services to meet caregiving needs, such as hiring domestic staff or utilizing childcare centers, preschools, or nursing services. In contrast, in lower-income households, the responsibility for caregiving predominantly falls on women, who are obliged to address these needs. This scenario presents adverse consequences on the labor participation of women with lower incomes, limiting their options to informal employment or underemployment. Additionally, it affects their opportunities to enhance their employability since they lack available time for training or job-related education.[33]

The feminization of primary or informal care, women's vulnerability to caregiving, and the care economy are important social determinants in primary or informal care. Each of them will be developed below.

The feminization of primary or informal care

Informal care has been almost exclusively required of women within the family, reflecting the widespread acceptance of the feminization of care and the attribution of family-centered responsibilities. It highlights the perpetuation of this discourse rooted in normality among those who perform caregiving roles.[29]

The traditional roles culturally framed for women produce deterministic stances that position them at a higher disadvantage not only to men but also to the same system that oppresses them in cultural, economic, political, and social

senses. Women's roles in the private-domestic sphere and their performance in unpaid work have been perpetuated over the years and continue to be the responsibility of women. Only on some occasions have men been co-responsible for managing a family and a home. In addition, the current globalized context obliges women to join the public-political sphere, specifically to engage in paid work in search of better living conditions without neglecting their family and domestic activities.[34]

The provision of informal care is influenced by gender inequality since it is mainly women who provide this care.[1,23] Consequently, women providing care face a higher impact on their health compared to men who also provide care.[35]

Vulnerability of women in primary or informal care

Vulnerability is a social phenomenon that implies a risk condition caused by social disadvantage accumulation. It encompasses a series of important factors, such as discriminatory behaviors and the marginalization of certain groups.[36]

Research indicates the existence of a triple vulnerability present in those who are routinely involved in the care of chronically ill patients, older adults, and people with disabilities. This vulnerability comprises three interrelated variables: gender, age, and poverty.[26]

Age is relevant when considering the age range of caregivers, which ranges from 15 to 64 years old[13,14,16,19], and approximately 52 years old, with a range of ±15 in primary caregivers of older adults.[15] It is frequent to find the presence of non-communicable chronic diseases, age-related frailties, and a lower resilience capacity against the adverse effects of the caregiver role.[26]

Poverty is another crucial variable. Women who cannot access the job market due to a lack of opportunities or age discrimination are considerably affected in their health and well-being. The lack of resources necessary to provide care leads to an increase in their levels of stress and frustration in performing their role as caregivers.[37]

The population with low economic income faces difficulties when assuming the role of caregiver, as the burden of care limits their participation in paid employment. Even when they work, it is challenging for them to save money for the future due to the resources required for caregiving and daily needs.[38]

For example, elderly individuals with low economic income who assume roles both as caregivers and care recipients face accumulated inequalities and experience high vulnerability to having their rights violated. This situation highlights the need to create a National Care System with a gender perspective, which can address these inequalities and ensure the well-being and protection of caregivers and care recipients.[22]

The national care system developed in Mexico is described below.

Vulnerability worsens in rural environments, as women providing care lack nearby access to health services, face a shortage of transportation, and are immersed in households where traditional gender roles are strictly ingrained. These factors hurt the caregiver's health by increasing the stress associated with caregiving or imposing this role as an obligation.[23,37]

The vulnerability of women in the context of caregiving is a relevant issue to consider. Women residing in rural areas often experience poorer psychosocial health compared to those living in urban settings.[39] Rurality increases this vulnerability, especially in households that adhere to strict and traditional gender roles, where women are expected to take on caregiving responsibilities. This imposition, combined with a lack of caregiving resources, negatively affects women caregivers' health, increasing the levels of stress and frustration.[23,37]

Vulnerability must be considered for assessing the level of impact on the health and well-being of women caregivers in rural areas. These caregivers require specialized attention from healthcare professionals, as they tend to experience a higher number of illnesses, psychological distress, less social support, and, above all, higher levels of anxiety and depression.[37]

Care economy

From a feminist perspective, the care economy is a point of view integrated into different contexts. It has helped to renew the feminist debate on the organization of social reproduction and to recognize how this influences the perpetuation of inequality. Care economy refers to how societies address the daily reproduction of individuals, the role this plays in economic functioning, and the factors that generate inequality.[40]

The feminist perspective emphasizes the need to consider the determinant role of gender relations to explain the concentration of women in caregiving activities and their minimal or less favorable participation in the labor market. It introduces the concept of the sexual division of labor as a widespread form to distribute time and types of work between men and women.[40]

The sexual division of labor becomes an organizing criterion that controls productive, biological, and economic activities. It socially and morally reinforces the assertion that tasks requiring dedication, especially those related to the healthcare field, are the responsibility of women.[41]

Despite the increased participation of women in the labor force in recent decades, concentrating on specific occupations and job categories, this incorporation represents a significant alteration in the gender division of labor in several countries. However, the distribution of domestic activities remains primarily the responsibility of women. It implies that women's entry into the labor market entails a double workload, emphasizing the importance of the global workload indicator to measure both domestic and labor market work comprehensively.[31]

Understanding the sexual division of labor involves analyzing elements related to reproductive functions and cultural distinctions between men and women. [31] Traditionally, unpaid work such as caregiving, attending to family members, emotional labor, household chores, time management,

household financial management, as well as marital and work demands has been attributed to women.[15,31,42]

In Mexico, studies on time use are scarce compared with developed countries. To a lesser extent, studies have been conducted to estimate the economic value of unpaid domestic work, and literature on specific aspects of time use is also limited. Some studies focus on analyzing the percentage of population participation in various activities, public and private, as well as the average time devoted to these activities. Women are at a disadvantage due to the inequality between women and men in this area.[43]

Surveys on time use allow visualizing the average hours dedicated to unpaid work by type of activity and gender (Figure 1), making the gender gap evident.[44]

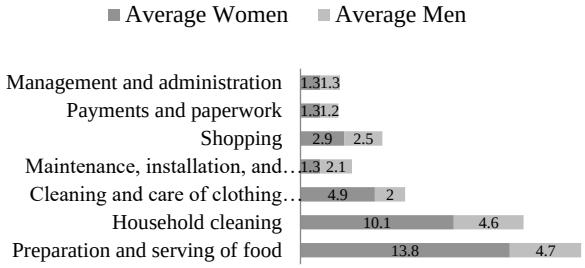

Figure 1. Average hours per week dedicated to unpaid work by type of activity and gender.[44]

GENDER PERSPECTIVE IN PRIMARY OR INFORMAL CARE

Gender perspective is a methodology that allows identifying, questioning, and evaluating women's discrimination, inequality, and exclusion based on biological differentiation from men. Moreover, this perspective focuses on analyzing mechanisms and measures related to gender factors to create conditions that promote changes for the construction of gender equality.[45]

Gender perspective requires considering inequalities in power, access to resources and control over them, the division of labor by gender, and gender socialization at all stages of health development. The gender perspective is relevant as it influences the effectiveness of interventions.[46]

The home and family environment serves as a space to carry out caregiving tasks, perpetuating and replicating cultural patterns that primarily assign women the responsibility for these tasks within the family sphere. The construction of gender identity in the context of caregiving entails an ongoing negotiation with family responsibilities.[47]

Even though it has not been explicitly expressed, there is an implicit implication that caregiving activities are exclusively the responsibility of women. This association stems from how these activities have been culturally and socially linked to the domestic sphere. Consequently, the responsibility for caregiving has been justified as primarily falling on women, despite the risks it poses to their physical and psychological health.[26]

The issue of primary caregivers must be approached from a gender perspective, as this theory allows us to consider additional factors contributing to the identified problems and highlights the vulnerability that impacts health and quality of life among primary caregivers.[1,23,26]

MEXICAN LEGISLATION REGARDING CARE

The General Law for Gender Equality contributes to caregiving by promoting gender equality and equitable access to healthcare services.[45] The General Law on Women's Access to a Violence-Free Life contributes to caregiving by providing protection, comprehensive care, promotion, and access to justice.[48]

General Law for Gender Equality. Its objective is to regulate and guarantee equality between women and men. It proposes institutional mechanisms and guidelines aimed at ensuring greater equality in both the public and private spheres and promoting women's empowerment. This law describes transversality as a process to ensure the incorporation of a gender perspective to evaluate its impact on women and men in any action: legislation, public policies, administrative, economic, and cultural activities in both public and private institutions.[45]

The General Law on Women's Access to a Violence-Free Life aims to prevent, punish, and eradicate acts of violence against women, adolescents, and girls. Additionally, it establishes the foundations and procedures to ensure full access to a life free from violence, protect and guarantee the whole exercise of their human rights, and strengthen the democratic system.[48]

The Federal Labor Law aims to regulate domestic work, obligating the employer to register the worker with the Mexican Social Security Institute and pay the corresponding fees according to applicable rules. It enshrines a legal definition of domestic workers, which includes those who carry out caregiving tasks.[49]

Constitutional Law of Human Rights and Guarantees of Mexico City: Article 56 states that the right to care includes the right of all individuals to take care of themselves, to care for others, and to be cared for. It comprises material care, which means working with economic value, and psychological care, referring to the emotional bond.[50]

Article 123 of the Mexican constitution establishes that, during pregnancy, women shall not perform tasks that pose a danger to their health concerning gestation; they shall enjoy a six-week rest period before and following the approximate date of childbirth, during which they must receive their full salary and retain their employment. During the breastfeeding period, they shall have two extraordinary breaks per day, each lasting half an hour, to feed their children.[51]

Programs comprising care policies in Mexico

Below are listed and briefly described some programs focused on care for specific populations.[33]

Care for early childhood, children, and adolescents:

- Childcare Centers Program: Monthly subsidy to cover childcare services in affiliated centers.
- Daycare Services of the Mexican Social Security Institute: Provides care during working hours for young children.
- Community Initial and Basic Education Program: It aims to strengthen educational attention for families in disadvantaged rural communities, to enrich child-rearing for the integral development of children under four years old, and access to quality education.

Care for older adults:

- Older Adults Pension Program: Targeted at individuals over 65 years old.

Single mothers:

- Contributes slightly to reducing the dependency on care that orphaned children may impose on close relatives, mainly grandparents.

Support for caregivers (Action, not program):

- Institute of Security and Social Services for State Workers provides online courses for informal caregivers.

Programs aimed at dependency and vulnerable individuals:

- Disability Care Program: Promotes the execution of projects that encourage social inclusion through action implementation.
- Support Program for People in Need: Aimed at individuals with disabilities, older adults, and women victims of crime and, or human rights violations.
- Scholarships for elementary education support for young mothers and pregnant women: It grants monthly financial and in-kind scholarships to individuals in vulnerable situations.

Direct employment programs:

- National Program for Financing Micro-entrepreneurs and Rural Women: Financial inclusion for individuals not eligible for commercial bank credit.
- Employment Support Program: Promotes the placement of unemployed or underemployed individuals in an occupation or productive activity.

NATIONAL CARE SYSTEM

The concept of caregiver is not established in Mexican legislation, which implies that there are no specific strategies or projects of public policy for individuals providing informal care to individuals with special needs, chronic or transitory illnesses.[52]

At the federal level, significant progress has been achieved with the recent approval of a constitutional reform regarding the National Care System. The main objective of this reform, which amends Articles 4º and 74º of the Mexican Political Constitution, is to ensure shared responsibility between women and men in caregiving tasks. This reform grants the freedom to decide whether to assume the responsibility of caring for those in need and the right to determine the distribution of one's time according to individual needs and interests. Currently, this initiative is pending ratification by the Senate.[53]

Furthermore, the State has been mandated to create a General Care Law, which, unlike a federal law, will require states to adhere to its provisions. This law includes the implementation of a national care system.[53]

Mexico's National Care System contains public care policies from a systemic perspective, a rights-based approach, and a gender perspective. It is grounded and has implications for the design and redesign of implementation and evaluation policies within the framework of human rights.[54]

Its components are as follows:

- Creation and expansion of services
- Regulation of working conditions for caregivers
- Training for paid caregivers
- Management of information and knowledge
- Communication to promote cultural change

CONCLUSION

The gender perspective is crucial for understanding the inequalities present in our society, especially regarding informal care. It allows for the analysis of issues, planning interventions, and reducing gender inequalities by more equitably distributing caregiving responsibilities, which would contribute to improving caregivers' health and quality of life. One of the main challenges of the gender perspective has been eliminating existing prejudices and resistance within the population to adopt this perspective. In Mexico, there is a crisis in caregiving, and to prevent caregiver overload, it is necessary to pay more attention to the needs of caregivers, change the social perception of women, modify the social, cultural, and health structure, and make changes in public policies to promote and guarantee the well-being of women caregivers. Women have gained more space in paid employment but still face the burden of activities assigned by the sexual division of labor and the resulting saturation of responsibilities. An ideological transformation and the implementation of individual and social actions are required within the family, the community, and the public health system to generate collective changes, aiming for equity in task distribution between genders, as well as health and well-being for all.

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