

Women caregivers: alone and overburdened

Submitted by bdesantiago on 18 April, 2023 - 11:23

Language English



NCD Alliance / Still from Facing Forward video series

No one is born knowing how to give care. We learn it, like everything. However, it's no news that women are more often the caregivers, they start at an earlier age, and they give more. It's not an opinion - the figures, information and history confirm it. And not only that, statistics and testimonials worldwide show that women who are informal caregivers earn less money, have less time to themselves, feel more alone and get sick more often.

When we talk about female informal caregivers we are referring to the overwhelming group of women who care for someone they love and are that person's only support in the face of illness, disability and emergency. They fulfill this fundamental role for their families and their communities, without training, without information, without social or professional protection; invisible, stumbling, failing and trying again.

The economy of care

Caregivers do work that generates immense value in social well-being. A figure that some studies estimated in Spain in 2014 (long before the pandemic that made everything worse), was of 40,000 euros [1 [1]] per person in a situation of dependency. In the United States, the value contributed by informal caregivers (75% of whom are women) totaled US\$470 billion in 2013. The value of unpaid care exceeded the value of paid home care and total spending on Medicaid in the same year, and nearly equaled the value of annual sales at Wal-Mart, one of the largest companies in the world, (\$477 billion). [2 [2]] In a 2019 study, the number of caregivers in Mexico was 90 million [3 [3]] people over the age of 12 doing care work in their homes without being paid, with 71% of the hours dedicated to this care covered by women. This enormous economic support from families goes unnoticed by the state. And on top of the hourly contribution are the added costs (of all kinds) that the caregivers "pay".

"Women perform more than 70% of unpaid care, and most of the time the work is made invisible along with the person who does it," says Irais Bonilla [4 [4]], president of Los Cuidados de Cuidar and organizer of the International Forum of Women Caregivers.

Caregivers "pay" the consequences of the lack of regulations that support caregivers, with only a few countries having poorly implemented and not very universal strategies (prevention, assistance, support, etc.) that do not protect caregivers from losing their jobs, their holidays, or having to give up positions of responsibility because they cannot reconcile the two tasks. In addition, caregivers gradually give up their free time, hobbies, and relationships due to the demands of care. They also pay with their own health, because they get physically and mentally ill as a result of their care work. Generally alone and overburdened, the caregivers are the most neglected.

The collective responsibility of care

The right to be cared for, to give care and to take care of oneself must be respected and highlighted in all health policies, in universal health coverage and in the care continuum.

Monin Piris, family caregiver and human rights activist in Paraguay, raises the urgent need to create a new care agenda that takes into account human rights and public policies. "Caring alone, without networks, without public policies, and without accessible services constitutes exploitation of women, in a romanticization of care."

Piris proposes de-romanticizing care, and also defamiliarizing it. For Piris, one of the pillars to work on is the myth of romantic love in which women are the ones who have to give care. We are bad daughters or bad mothers if we don't want to care to our limit. "The myth of romantic love has supported all the violence, all the exploitation, all the discrimination and also the work of caregiving for women. We have to end this concept of care and how it is structured, because it does not guarantee rights to the people being cared for, nor to the families, nor to us. Care in our societies is sustained through the exploitation of women." [5 [5]]

Within the framework of the Forum, Ana Laura Baez, nurse and formal caregiver and member of the Latin American Network of Caregivers (RLC), says that the person who gives care is also wounded, her heart is wounded because she loves the person she cares for. Claudia Ramos Enciso, also from the Network, says she has been a caregiver "all her life", and today works as a caregiver. "The work is learned but the understanding of how we should take care of ourselves is what is important, because most of us are wounded caregivers."

A caring society

The impact and number of unpaid caregivers is growing around the world, but this is not reflected in public policies for caregivers. A 2022 *Frontiers in Public Health* report [6 [6]] indicates that where these types of policies exist, they either do not focus on caregivers or are fragmented, incoherent, and rendered useless. Even in countries where there are well-developed services, such as Australia, 80% of care is provided by families.

Policies for caregivers should not only ease the burden and meet needs, but should also support caregivers so they can flourish as people. Currently, there is little consistency in global policies and programs to support caregivers and there is no common framework. But, as Monin Piris says, it's not just about achieving better conditions for caregivers or providing training on how to care or being paid; women and their needs must be at the center of policies. "I want to give care, I want to be taken care of and I want the state to take care of me. We have to propose a caring society."

The care agenda has to be integrated into the Human Rights agenda, into the Universal Health Coverage agenda, because women do not want to continue caring alone in a system "that does not recognize us, that is killing us, not only us, but also abandoning the people that we are caring for."

About the author:

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Published on NCD Alliance (<https://ncdalliance.org>)

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[2] <https://www.caregiver.org/resource/caregiver-statistics-demographics/>

[3] <https://library.fes.de/pdf-files/bueros/mexiko/15303.pdf>

[4] <https://plenitudydemencias.org/>

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