Anduli
Revista Andaluza de Ciencias Sociales
ISSN: 1696-0270 • e-ISSN: 2340-4973

CARING BODIES: WOMEN’S INVISIBLE LABOR AND GENDERED CAREGIVING IN THE TURKİSH DISABILITY CONTEXT

CUERPOS QUE CUIDAN: EL TRABAJO INVISIBLE DE LAS MUJERES Y EL CUIDADO DE GÉNERO EN EL CONTEXTO DE LA DISCAPACIDAD EN TURQUÍA

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Abstract

Disability care provides essential support to individuals unable to manage daily life independently. Women caring for children with disabilities often perform informal caregiving alongside domestic duties, which makes their work more labor-intensive and reinforces gendered labor divisions. In Turkey, caregiving is largely seen as women’s responsibility, shaped by traditional norms and policies. This study explores the experiences of 18 female caregivers in Bandırma, Balıkesir province, from a gender and citizenship perspective. It establishes that caregiving, without institutional support, exacerbates women’s economic hardship, social isolation, and physical exhaustion, while also limiting access to citizenship rights. While financial assistance, such as the home carer’s allowance, offers relief, it reinforces traditional roles and limits caregivers’ personal and professional opportunities. Framing care labor within broader debates on gender and citizenship, this study emphasizes the urgency of a rights-based approach that includes social security, accessible services, and legal protections to reduce caregivers’ burdens, foster inclusion, and ensure the well-being of caregivers and care recipients.

Keywords: Care Labour, Disability Care, Home Care, Corporeal Care, Care Policy

Resumen

El cuidado de discapacitados proporciona un apoyo esencial a las personas incapaces de desenvolverse de forma independiente en la vida diaria. Las mujeres que cuidan de niños discapacitados suelen realizar esta labor de manera informal, junto con las tareas domésticas. En Turquía, la prestación de cuidados se les atribuye a las mujeres y se rige por normas y políticas tradicionales. Exploramos las experiencias vividas por 18 cuidadoras en Bandırma (Balıkesir), desde perspectiva de género y ciudadanía. Se establece que la prestación de cuidados, sin apoyo institucional, agrava la precariedad económica, el aislamiento social y el agotamiento físico de las mujeres, al tiempo que limita su acceso a los derechos de ciudadanía. Si bien las prestaciones para cuidadores a domicilio ofrecen un alivio, refuerzan los roles tradicionales y limitan las oportunidades personales y profesionales de los cuidadores. Se recomienda resolver el problema adoptando un enfoque basado en los derechos que incluya seguridad social, servicios accesibles y protecciones legales.

Palabras clave: *Trabajo de Cuidados, Cuidado de discapacitados, Cuidados a domicilio, Cuidados Corporales, Políticas de Cuidado*

Citation/cómo citar este artículo: Dogruel, Fulya (2025). Caring bodies: women´s invisible labor and gendered caregiving in the Tukish disability context.
ANDULI 28 (2025) pp. 177-195, https://doi.org//10.12795/anduli.2025.i28.07

Recibido: 26.01.2025; Revisado 26.03.2025; Aprobado: 14.05.2025.

1. Introduction

Care work is inherently gendered and feminized, largely assigned to women due to socially constructed roles and expectations. Traditionally linked to emotions and care, women are expected to assume caregiving as a natural duty. However, care work extends beyond physical labor, encompassing social, emotional, and economic dimensions (Chen et al., 2025; Twigg, 2004). Informal care work is largely assigned to women under the assumption that they possess an inherent ability to provide care. Caring for individuals with disabilities constitutes one of the most demanding aspects of women's caregiving responsibilities, consuming significant time and effort. Women who care for children with mental or physical disabilities not only engage in unpaid care work but also shoulder household responsibilities, ensuring the continuity of family life. The feminization of care and its transformation into a burden remain critical issues, highlighting the challenges faced by women caregivers.

Care work, traditionally conducted within a solidarity network of the extended family (Nash, 2014, p. 26), has undergone significant transformation through modernization processes. This shift not only isolates caregiving responsibilities onto a single individual but also reinforces the burden placed on women, who are often expected to embody the impossible demands of care work, as reflected in phrases like "performs the impossible; works at lightning speed" (Caregivers Nova Scotia, 2024) and "shovel prisoners of care work" (Özateş Gelmez, 2014).

Caring for individuals with mental illness presents unique challenges, not only due to the symptoms of the conditions themselves but also because of the societal stigma surrounding mental illness. Caregivers face heightened risks of anxiety and depression, yet their mental health remains largely overlooked in social discourse (Chen et al., 2025; Isaac et al., 2022). This neglect exacerbates systemic inequities and perpetuates gender-silent narratives that fail to address the broader relational and political dimensions of caregiving (Funk et al., 2024, p. 6).

The global crisis of care affects not only family caregivers but also paid care workers. With increased migration from the Global South to the Global North, care labor is increasingly commodified at progressively lower wages. At the same time, there is a growing need for an inclusive, rights-based approach to social care policies (Chatzidakis et al., 2020).

In Turkey, over 2.5 million individuals are registered in the National Disability Data System, with severe disabilities affecting approximately 775,000 people (Ministry of Family, 2023). The sharp rise in applications for the carer's allowance—from 8,877 in 2007 to 100,812 in 2022—reflects the increasing reliance on home care services. These figures underscore the significance of caregiving as a central societal issue.

This study examines the impact of informal caregiving on women caring for children with disabilities, with a focus on the social, psychological, and economic challenges they encounter. It investigates how these caregiving responsibilities intersect with gender and citizenship, shaping women's societal participation and limiting their access to essential rights and resources. The findings reveal the complex ways in which the absence of institutional support and restricted access to citizenship rights exacerbate caregivers' economic precarity, social isolation, and physical strain. These insights call attention to the urgent need for a solution-oriented approach to inform policy changes that alleviate caregivers' burdens and promote greater social inclusion.

Understanding Caregiving: A Theoretical Exploration

Studies on care work seek to understand its essence, reveal the substantial responsibilities of caregivers, highlight the persistent gendered division of care despite policy advancements, expose the deprivations and health challenges faced by caregivers, and examine their civic rights. A comprehensive theoretical framework must address care labor, the feminization of care, care burden, care policies, and citizenship.

1.1. Care Labour and the Feminisation of Care

Women have historically been positioned as primary caregivers, a role embedded in societal expectations, particularly for elderly family members and individuals with disabilities (Funk et al., 2024; Bezmez & Porter, 2022). This divide is a systemic issue rooted in broader socio-economic structures. “Globally, women perform 76.2% of unpaid care work—over three times more than men” (Addati et al., 2018 in Fast et al., 2024, p. 238). Despite its economic significance, care labor remains undervalued (Funk et al., 2024).

Economic policies and public spending cuts deepen disparities by shifting care responsibilities onto families, particularly women, as seen in Brazil (Coffey et al., 2020). In Canada, the privatization of eldercare has further entrenched reliance on unpaid female caregivers (Armstrong & Braedley, 2023 in Funk et al., 2024, p. 2). This care work, whether paid or unpaid, involves meeting the physical, psychological, and emotional needs of care-dependent groups (Wray et al., 2023, p. 7). Similarly, in Turkey, cultural norms designate women – especially mothers – as primary caregivers, limiting their economic participation (Bezmez & Porter, 2022, p. 15). Structural inequities are particularly evident among mothers of children with disabilities, who face significantly lower employment rates due to caregiving responsibilities. As Ehrlich et al. (2020, p. 1388) argue, “women with caregiving duties are significantly less likely to participate in the formal labour market, perpetuating cycles of economic dependency.”

Recognizing care labor as an economic contribution is essential for gender justice (Phillips et al., 2023, p. 54). Policy reforms—state-supported care services, paid leave, and care infrastructure—are critical to alleviating women’s disproportionate burden (Ehrlich et al., 2020). Without systemic change, gendered inequities in caregiving will persist (Chatzidakis et al., 2020, p. 92).

2.2. Care Burden and Burnout

Caregiving is physically and emotionally demanding, with significant health, social, and economic risks. Concepts like “burnout” and “care burden” highlight its adverse effects on well-being, family relationships, and financial stability (Zarit et al., 1980; Pearlin & Aneshensel, 1994). This strain is particularly severe for those juggling both employment and unpaid care responsibilities. Women, assuming most caregiving duties, report heightened stress, mental health deterioration, and financial instability (Bezmez & Porter, 2022; Knaifel & Rubinstein, 2024).

Financial strain further limits labor market participation (Elayan et al., 2024; Hess et al., 2022). Framing care as an individual responsibility overlooks how power dynamics and resource inequalities shape caregiving, shifting the burden onto the most precarious women, who often work informally without employment protections like unemployment insurance or pensions (Greenhough et al., 2023; Kalaycıoğlu et al., 2016) thereby restricting their economic independence and civic participation.

Underfunded care services create a “care crisis,” where unpaid caregivers compensate for systemic gaps at great personal cost (Fast et al., 2023, p. 237). In Turkey, unpaid family members carry most of the burden. Prolonged caregiving increases stress, anxiety, and depression (Chen et al., 2025; Bistaraki et al., 2025). Caregivers also face social isolation due to stigma surrounding mental illness and disability (Phillips et al., 2023), limiting self-care and social activities (Alghamdi et al., 2025).

Addressing care burden requires financial support, expanded public care infrastructure, and workplace accommodations (Clough, 2021). As suggested by Kolacka et al. (2025) and Backhouse et al. (2022), a holistic approach that recognizes caregivers’ contributions is essential for sustainable care provision.

1.3. Care, Women and Citizenship

The feminization of care necessitates a reexamination of its intersection with democratic citizenship, particularly in neoliberal economies that commodify care while devaluing unpaid labor. As Elayan et al. (2024, p. 1324) note, “the commodification of care labor and the marginalization of unpaid work restrict women’s economic independence and limit their civic engagement”

Parents of children with disabilities face barriers to employment and social participation, “which may hinder their involvement in health-promoting behaviors” (Alghamdi et al., 2025, p. 75). Care responsibilities shape women’s citizenship by restricting access to social and economic rights, as “caregiving takes time, and when duties become extensive, many caregivers cut back time in paid work” (Hess et al., 2022, p. 7), reinforcing financial precarity. Perry-Jenkins and Gerstel (2020) stress that caregiving’s systemic invisibility in public policy, necessitates legislative frameworks recognizing care as a societal responsibility.

Turkey exemplifies these dynamics, as women disproportionately shoulder caregiving duties while disabled individuals and their caregivers remain “profoundly excluded from education, the labor market, and urban spaces” (Yardımcı & Bezmez, 2018, in Bezmez & Porter, 2022, p. 57). Conservative and neoliberal ideologies frame care as a familial or market-based duty rather than a collective social obligation (Sallan Gül, 2014; Funk et al., 2024). Research links parental life satisfaction to the availability of leisure time, emphasizing the need for institutional support (Kołacka et al., 2025).

Addressing these inequities requires reframing care as a collective responsibility. Feminist scholars emphasize that policies such as paid family leave, care credits, and childcare and eldercare investments are crucial for gender equity (Hess et al., 2022). As Elayan et al. (2024, p. 1324) note, “millions of caregivers make significant personal sacrifices, dedicating billions of euros’ worth of time and resources to providing care”, yet their contributions remain economically unrecognized. Without structural reforms, caregiving will continue to reinforce economic marginalization and social exclusion. Citizenship must be understood “not simply as a legal status but as political and social recognition and economic redistribution” (Isin & Turner, 2002, p. 2).

In summary, caregiving remains undervalued, disproportionately affecting women’s social, emotional and economic standing. Implementing flexible work arrangements, caregiver assistance programs, and comprehensive care policies is essential for fostering a more just society.

2. Methodology

This qualitative study, conducted in the Bandırma district of Balıkesir province between February 10 and July 10, 2022, is based on face-to-face in-depth interviews with 18 women providing care for children with mental disabilities. As an industrial hub with factories and a port, Bandırma attracts migration from nearby towns and villages, blending rural and urban cultural characteristics. This transitional nature makes it a representative site for exploring care work at the intersection of traditional gender roles and contemporary expectations. Qualitative research was selected for its capacity to "uncover the meaning of a phenomenon for those involved" (Merriam, 2009, p. 22).

For data collection, a semi-structured interview format consisting of 18 open-ended questions was employed. Participants were selected using the snowball sampling technique. Participation was voluntary, with careful attention paid to ensuring the collection of participant information and opinions in accordance with the principles of anonymity, confidentiality, and privacy (Neuman, 2020, pp. 149, 152). The study's reliability and validity were enhanced by ensuring sufficient participation, encompassing diverse experiences, and examining the phenomenon holistically and multidimensionally (Merriam, 2009, pp. 213–215).

The female participants, aged 28 to 65, generally had low levels of education: two were illiterate, one had completed secondary school, eight primary school, four high school, and three had attended university. The majority were married housewives, while four had previous work experience—two of whom left their jobs to provide care. All participants care for children with mental disabilities that require constant and complex medical attention. Many also struggle with their own health conditions, necessitating regular check-ups, treatment, and care.

2.1. Research Focus and Questions

The semi-structured interview guide, outlined in the methodology section, explores four key themes to enhance transparency. The first part, entitled *Responsibilities of Caregiving*, included questions about the participants' caregiving responsibilities and their daily routines. It also addressed their perceptions of caregiving sufficiency and whether they felt the need for additional training or support. The second part of the questionnaire, *Challenges in Caregiving*, asked participants about the physical, emotional, and social difficulties they encountered in their caregiving roles. The questions explored issues such as health concerns, the impact of caregiving on their social lives, and the adequacy of available economic resources.

The third and final section, *Opportunities for Capacity-Building*, explores the participants' efforts to enhance their social, cultural, and economic capacities while fulfilling caregiving responsibilities. It also invited them to share their future plans and recommendations for improving caregiving conditions through support and capacity-building initiatives.

3. Data and Findings

This section, drawing on interviews with women caregivers, explores their lived experiences of providing informal care for physically and/or mentally disabled children. The findings are organized into four interrelated key themes. The study examines, first, the gendered nature of caregiving in daily routines; second, the burdens and emotional toll caregiving entails, particularly under conditions of limited institutional and social support; third, the broader economic and policy context of caregiving, focusing on the limitations of the welfare regime and the informalization of women's labor; and finally, the intersection of caregiving with citizenship and labor rights, highlighting women's collective struggles for recognition and structural change.

3.1. Women's Informal Care Work in Everyday Life

Care work is multidimensional, particularly when undertaken by a housewife who must manage both familial responsibilities and caregiving throughout the entire day. Around the globe, women consistently play a pivotal role in providing care services, accounting for the vast majority of unpaid care labor. Studies show that women perform the majority of personal-care tasks and spend significantly more time on caregiving than men (Fast et al., 2024). Care is a labor-intensive and ongoing process. There are no breaks, escapes, or opportunities for rest, and maintaining a deep or regular sleep rhythm is challenging. Participants providing disability care report a demanding 24/7 routine. They describe this intense workload as follows:

> *I prepare breakfast, dress up the child, and the school bus picks him up. Then I prepare lunch for my husband to eat at work. Afterward, I tidy up, light the stove, put coal in, do the dishes, and prepare the child's belongings. I take my medication. In the afternoon, I take the child to the rehabilitation center. If there is a training course I attend it for the child. When I return, I prepare dinner, put away the dishes, and put the child to sleep. I can't spare any time for myself. I feel inadequate. (P7, 44, Literate, Housewife)*[1]

> *There is not enough time. If you try to have quality time with the child and have fun, the house falls apart … everyone is happy, but I am unhappy. After all, I must tidy up the house. I pretend to be happy. It is a senseless state of depression. (P16, 44, University, Employee)*

This lived experience is reflected in statistical findings. According to the Turkish Statistical Institute (TÜİK, 2011), mothers provide 81.5% of primary care for children with mental disabilities, while fathers contribute only 3.7%. Although more recent data on caregiving for individuals with disabilities is limited, existing figures continue to illustrate the disproportionate caregiving burden shouldered by women. TÜİK's Statistics on Women (2022) show that 94.4% of childcare and most domestic duties are still managed by women. This exhaustive workload, which extends around the clock, not only affects caregivers' health but also limits their ability to maintain a regular sleep pattern or attend to their own needs.

Beyond time use, the literature emphasizes the significant emotional and physical burdens shouldered by caregiving mothers, including fatigue, mental distress, and reduced family well-being (Öztürk & Alemdar, 2023; Tuncay & Sarman, 2024). These findings emphasize the urgent need for comprehensive policy support.

In general, the lack of spousal support and relationship tensions are commonly identified as major stressors for caregivers (Kara & Alpgan, 2022). Fathers' involvement is often limited to roles like shopping or transporting the child to medical appointments, which align with the traditional gendered division of labor. Meanwhile, mothers face multifaceted challenges in caring for children with mental disabilities. In addition to daily domestic chores, disability care – like elder care – requires attention to physical, emotional, and social needs. Caregivers provide not only practical assistance, such as

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[1] Participants are defined in terms of their age, education, and profession.

feeding and cleaning, but also extensive emotional labor, offering comfort, protection, and support. This labor, though essential, remains socially undervalued and largely invisible (Funk et al., 2024; Coffey et al., 2020; Özateş Gelmez, 2015).

> *My child forgets quickly; I must teach the same things repeatedly. He has speech disability and a physical disability. He is not well-balanced and has panic attacks. He hits me when he gets angry and displays aggression when he wants something. He is unable to feed himself. I abandon my meal and revert to him. It would be nice if his father fed him one bite. His father has not even once cleaned the child after the child has gone to the toilet. (P12, 51, Primary School, Employee)*
>
> *I've spent my life with doctors. It is necessary to take him for a check-up every 5-6 months to Bursa [a neighboring city]. I have sole responsibility. Sometimes my mum helps me (P15, 40, Primary school, Housewife)*
>
> *Men help, but not like women, since they work, they can only take them out on Sunday's. They usually leave it to the women. (P14, 47, University, Former employee)*

Care work for the disabled and the ill at home is primarily assigned to women, and they remain bound to this role until either they or their disabled children pass away. Three participants, currently employed or having worked previously, continue to receive long-term support from their mothers in caring for their disabled children. This reveals the persistence of women's invisible labor. In this context, the care of disabled individuals, mostly handled within the family by women, is seen as a practical solution. However, it not only 'isolates' women from the public and economic spheres (Knaifel & Rubinstein, 2024), but "empirical evidence has consistently demonstrated the negative impact that caregiving can have on an individual's health and well-being across multiple areas" (Cheshire-Allen & Calder, 2022, p. 51)."

3.2. From Care Giving to Care Burden

The challenges faced by women providing care services are profound and multifaceted. As the first influential studies in caregiving literature illustrate, due to caregivers' shifts lasting both day and night and their responsibility for the care and service of not only the disabled but also all individuals in the household, the time they can allocate to rest or attend to their individual needs and interests is either very limited or non-existent (see also Sörensen et al., 2006; Pearlin and Aneshensel, 1994; Zarit et al., 1998). Due to the workload, women's social and private lives are adversely affected.

They struggle to find long-term solutions to their problems, worry about the future, lack the necessary energy and synergy to develop support strategies making their lives easier, and are left grappling with social isolation, insomnia, and depression.

> *My child is 90 percent severely disabled. When you work, you are separated for a long time, and you always wonder if something is amiss at home. My mother was bedridden, needing care. Taking care of both my child and my mother was very difficult. I had to find a solution, but I had a nervous breakdown … fatigue increases with age. (P2, 50, University, Retired)*
>
> *You want to go somewhere, you can't go, you want to watch a film with your spouse, you want to meet your friends, you can't go because he can't cope with the environment, and even if you go, you don't enjoy it. The child experiences anger and joy at his peak. Others may find it difficult to understand him ... we also deal with social pressures. (P10, 42, Secondary School, Housewife)*

> *We feel like the living dead; we are not alive. We also want to travel; we also want to rest. (P8, 57, Primary school, Housewife)*
>
> *We struggle with fatigue, not being supported, feeling alone. (P7, 44, Literate, Housewife)*

This state of physical and emotional burnout reflects broader patterns of deprivation, where caregivers face shortages in support, health, and personal time. Structural inadequacies in public care further exacerbate this strain intensifying the burdens on women caregivers. Recent studies emphasize the multifaceted challenges that caregivers encounter, particularly in terms of social, health, and financial well-being (Fast et al., 2024; Duncan et al., 2020; Cheshire-Allen & Calder, 2022; Özateş-Gelmez, 2014). Women caring for disabled children often experience social isolation and limited access to economic, cultural, and emotional capital essential for well-being (Bourdieu, 1986). In this study, participants primarily derive emotional capital from the honor they receive, with patience seen as key to this recognition. However, some prioritize financial support over emotional rewards.

Caregivers often struggle with worry, sadness, and helplessness, particularly when their loved ones are unaware of their condition, as also observed by Chen et al. (2025). Economically, caregiving restricts employment opportunities, increasing financial strain on families (Alghamdi et al., 2025). As Pinquart and Sörensen (2004, p.33) note, caregiver “women had higher levels of burden and depression, and lower levels of subjective well-being and physical health. So, caregivers experience significant negative impacts on their ‘health, wealth, and social relations” (Cheshire-Allen & Calder, 2022, p. 51). This emotional and financial burden is further reflected in caregivers’ lived experiences, as illustrated by the following participant.

> *When I was receiving a care allowance, I felt uneasy, as if I were committing a sin – taking care of my child for money. When the care allowance was stopped, I felt relieved. (P6, 48, Primary school, Housewife)*

However, the awards, especially the ‘good’ and ‘caring mother’ honors bestowed upon mothers of the disabled within the context of social culture and beliefs, appear insufficient to repair the emotional, psychological problems and burnout states they experience. Many participants expressed the need for psychological support to cope with the challenges they face. Overall, it is evident that caregiving carries serious negative psycho-social repercussions, as revealed in other studies as well (Gérain and Zech, 2019; Sörensen et al., 2006; Brunner and Marmot, 2009), leading to depression, anxiety disorders, and chronic stress-related health issues among those burdened by it.

> *Every morning when I wake up, I say, ‘God, grant me patience, give me strength to endure... I am also dealing with social pressure. (P11, 42, High School, Former employee)*
>
> *The burden we bear is unique, significant; I think ‘my child comes before me.’ They approach us, mothers of the disabled, with empathy. When we part ways, they say, ‘May God give you patience.’ Now, I affirm that my child is the reason I find strength. However, after a certain point, we, too, face psychological challenges. (P5, 60, High School, Housewife)*
>
> *I don’t receive psychological support, but I do need it from time to time. I cry and try to manage to get through it. We all need a psychologist. I wish a psychologist could*

> *be provided for us. Unfortunately, we cannot afford it. (P9, 52, Primary school, Housewife)*

On the other hand, negative physiological effects of caregiving appear to compound the burden, as participants reported having more than one concurrent disease, including lumbar-neck hernia, diabetes, blood pressure issues, cardiovascular diseases, cardiac arrhythmia, and cancer. Additionally, some participants mentioned that they struggled to find time to receive necessary treatment when they fell ill, even postponing necessary surgeries.

> *I have a looming risk of the herniated disc bursting, and I desperately need an operation. This child is very difficult; who else but me can look after him? The father is already angry; men don't involve themselves in caregiving because they work... I struggle to sleep at night; I broke out in hives from stress. (P7, 44, Literate, Housewife).*

> *I have become disabled due to illness, having heart rheumatism and muscle diseases, and I am trying to take care of my child. (P17, 66, Primary school, Housewife).*

It is observed that women who strive to protect the health of their families are unable to safeguard their own health. Often neglected as invisible patients with chronic illness, caregivers experience a decline in their physical, cognitive, and mental health as the burden of care increases. Low levels of education and income are factors that worsen health status and quality of life among informal caregivers (Elayan et al., 2024; Chen et al., 2025; Cheshire-Allen & Calder,2022). This finding is also reflected in studies conducted in Turkey (Bezmez and Porter, 2022; Baysan and Mandıracıoğlu, 2021; Özateş Gelmez, 2015). Care burden, burnout, availability of psychological and social support, and economic conditions are crucial determinants of the quality of life for both individuals with disabilities and their caregivers. When institutional needs are not adequately met, individuals' financial capacities may also prove insufficient. Hence, it becomes apparent that caregivers necessitate both social and institutional support within the framework of more inclusive social policies to foster resilience and promote healthier lives.

3.3. Unveiling Women's Care Labor within the Economics of Care

The family remains at the heart of Turkey's welfare regime, a structure shaped by globalization and neoliberal policies. These shifts have raised concerns about the erosion of social rights, particularly in relation to care labor (Buğra & Keyder, 2006). Care services, social assistance, and the social security system form key pillars of Turkey's social policy framework. One notable initiative, the 'home carer's allowance' (introduced in 2006), aims to reduce institutional care needs by supporting informal caregiving within families. This allowance is intended to ease financial burdens on families caring for individuals with severe disabilities, yet it is contingent on strict eligibility criteria: a household income below two-thirds of the minimum wage and a medical report confirming at least 50% disability (Ministry of Family, 2024).

Despite its intent, many participants found the carer's allowance insufficient to cover caregiving expenses. Respondents highlighted the financial strain involved in meeting the needs of disabled family members:

> *My child is severely disabled. His diet is special, his clothes wear out quickly from constant washing, and medicines are expensive. If we go to the hospital, I take a taxi if it's cold; otherwise, we take the bus. The allowance is not enough. (P3, 58, Primary school, Housewife)*

> *A lot is needed—wheelchairs, food, psychological support. His prosthesis is old; he needs a new one. Even in the disabled café, tea is not discounted for the disabled. (P5, 60, High School, Housewife)*

These accounts expose the limited scope of state assistance, which, rather than alleviating financial hardship, often exacerbates gender disparities, particularly for low-income households (Hess et al., 2022; Funk & Hounslow, 2021). The rigid income-based eligibility criteria further limit access to support. Some participants reported being denied the allowance due to minor classification discrepancies in disability reports:

> *I cannot get an allowance because my child's disability report does not mark 'special needs,' yet I assist with dressing and toileting. I dared not contest it for fear of losing rehabilitation support. If my child is diagnosed as disabled, shouldn't they receive an allowance? (P10, 42, Secondary school, Housewife)*

Other participants described unintended financial trade-offs:

> *My daughter received an allowance, but she was removed from her father's National Insurance and placed on the Green Card scheme. We were shocked to find we had to pay for her medication in full. We had to choose between the disability allowance and health security. (P13, 58, Secondary school, Housewife)*

Beyond financial constraints, caregiving responsibilities remain deeply gendered. The expectation that care work should be provided within the family, without institutional or financial support, disproportionately burdens women. These findings are consistent with extensive research, including studies by Özateş Gelmez (2015), Duncan et al. (2020) and Fast et al. (2024) all of which argue that unpaid caregiving reinforces gender inequalities. Studies show that women performing unpaid care work often withdraw from the labor market due to the absence of formal support structures (Funk et al., 2024; Kalaycıoğlu et al., 2016; Hess et al., 2022; Ehrlich et al., 2020), limiting their economic independence and social mobility (Chatzidakis et al., 2020).

Women receiving care allowances are classified as employed by TÜİK, yet they lack formal labor protections (Toksöz, 2014). Expanding home-based care in the disability sector has made unpaid domestic labor more visible and compensated. However, this does not guarantee women's right to work, as those receiving care payments remain without essential labor rights like regulated hours, social security, and paid leave, contrary to Turkey's ILO commitments (Altuntaş & Atasü-Topcuoğlu, 2016, p. 9, 17).

In effect, they serve as informal state employees, providing care without access to unemployment insurance, pensions, or other essential benefits—reinforcing their economic precarity. The exclusion of caregivers from mental health systems and social support networks exacerbates their vulnerability (Chen et al., 2025). As Elayan et al. (2024) emphasize, comprehensive family and professional support systems are crucial for alleviating these burdens. Meanwhile, the high costs of care, coupled with limited opportunities for caregivers to improve their earning potential, reinforce their economic exclusion (Cheshire-Allen & Calder, 2022).

The prevailing model of care, framed as state-provided cash aid rather than a fundamental right embedded in social security, perpetuates the marginalization of women caregivers (Funk et al., 2024; Perry-Jenkins and Gerstel, 2020). This approach fails to recognize the true costs of caregiving, often resulting in a form of public patriarchy where women are expected to shoulder caregiving responsibilities in isolation. While the Ministry of Family offers psycho-social support services and rehabilitation courses, these measures often fall short. Mentally disabled children typically receive only twelve hours of state-supported rehabilitation per month, which is insufficient to meet their needs or provide relief to caregivers.

Participants expressed a need for more accessible and comprehensive support systems, such as daycare centers or respite care facilities:

> *If schools and rehabilitation centers were always open, it would provide relief for both me and my child. (P14, 47, University, Former employee)*
>
> *We need a place where we can leave our children, like a school or daycare center, where we can drop them off and pick them up. (P6, 48, Primary school, Housewife)*
>
> *Our biggest challenge is keeping them occupied. We send them to school so they can socialize. We are old, and they are the children of the state, right? The state should be involved. (P9, 52, Primary school, Housewife)*

These testimonies reveal the urgent need for institutional reforms that provide caregivers with structured, state-supported assistance. The absence of adequate support not only increases caregivers' isolation but also reinforces their exclusion from formal employment (Hess et al., 2022; Chatzidakis et al., 2020). The caregiving crisis, particularly for women in unpaid roles, requires immediate legal and policy interventions (Hess et al., 2022).

In conclusion, while Turkey's welfare model provides some financial support for informal caregivers through programs like the 'home carer's allowance,' it remains insufficient in addressing the full spectrum of caregiving needs. The reliance on women to perform unpaid care labor without adequate financial or institutional backing perpetuates gendered inequalities and deepens economic precarity. Comprehensive reforms are urgently needed to recognize caregiving as a fundamental right, ensure fair compensation, and provide caregivers – particularly women – with access to professional development opportunities and social security benefits. Reshaping the economics of care is essential for fostering an equitable system that upholds the dignity of both caregivers and care recipients.

3.4. Women's Care Roles through Citizenship and Labour Perspectives

The unending overtime of informal caregiving, which subsequently marginalizes individuals in various aspects of life, emphasizes the impossibility of undertaking this task in any private or public institution. It becomes evident that the ability of women providing informal care services to exercise basic citizenship rights is limited in situations where women solely undertake caregiving responsibilities within the family, without the knowledge, interest, and general support of the public, and without a profession or a regular income.

The disproportionate burden of caregiving on women, particularly in home care for the disabled and sick, poses significant challenges to their citizenship rights. Citizenship, as defined by Marshall (1950) and the Universal Declaration of Human Rights (UDHR), encompasses civil, political, and social rights, linking them to broader societal participation. It shapes individuals' roles and relationships in the public sphere, forming the foundation for participation, representation, and policy development (Nash, 2014; Isin & Turner, 2002; Janoski & Gran, 2002). In line with the UDHR, the Turkish Constitution (Articles 10, 17, 60, and 61) guarantees fundamental rights such as equality before the law, the right to life, social security, and protection of the disabled (Official Gazette, 1982; UN, 1948). Women providing informal care services often struggle to exercise their rights, especially when they bear caregiving responsibilities alone without public support, professional engagement, or financial independence.

The lack of institutional support marginalizes caregivers, particularly women, by limiting their rights, resources, and social participation (Allen and Calder, 2022; Fast et al., 2024; Duncan et al. 2020). This deepens their economic vulnerability and raises concerns about women's citizenship rights. Addressing these challenges requires stronger social security, rehabilitation programs, and childcare services to ensure a more equitable care framework. Meanwhile, precariously employed female caregivers recognize the value of paid work and stress the need for social protections. The lifelong demands of caregiving, often leading to health complications, highlight the urgency of pension and healthcare security, especially as caregivers age. This tension is evident in their experiences, as they navigate caregiving responsibilities alongside aspirations for financial independence and stability. Participants reflect on the difficult choice between work and caregiving, highlighting the personal sacrifices involved. For many women, this burden extends over decades, leaving them without financial security in later life.

> *I was working. My parents took care of the baby until it grew up… I quit when my mum said I could not take care of her anymore. I wish I could improve myself, do something, but I can't anymore. (P14, 47, University, Former employee)*

For others, caregiving has defined their entire working lives, depriving them of the opportunity for financial independence and retirement security.

> *I am a housewife for 50 years, I take care of the disabled, if I had worked, I would have retired, we couldn't work because of them, if we had worked, we would have received a pension, don't we deserve it? (P17, 66, Primary school, Housewife)*

Beyond financial insecurity, caregiving imposes structural limitations on employment, reinforcing economic dependence. Another participant emphasizes the long-term sacrifices, describing how caregiving responsibilities restrict labor force participation and leave families vulnerable:

> *We care for our children, so we are unable to work. My husband works when he finds a job, he works, and if not, he is unemployed. Currently, my son is also unemployed. If my child did not require constant care, I would seek employment with National Insurance coverage. I am not free. We are tied to these children; this restricts our ability to pursue other employment opportunities and leaves us without job security. I would like the state to provide National Insurance for all mothers of disabled children. Mothers should have such a right. We do not know if our children will be able to look after us in the future. We do not know what will become of us tomorrow. (P7, 44, Literate, Housewife).*

This statement spotlights the profound personal and systemic challenges faced by women in caregiving roles, emphasizing how these responsibilities extend beyond individual families and reflect larger societal issues. Women in caregiving find themselves caught in a cycle of uncertainty, both for their own future and that of their disabled children, despite making essential yet unpaid contributions to the labor system. Their caregiving labor is essential for sustaining households, yet it remains largely invisible and unrecognized. Care work is not merely a personal or familial responsibility but a structural issue deeply embedded in broader socio-economic systems (Ehrlich et al., 2020). As Isin and Turner (2002) and Nash (2014) argue, neoliberalism marginalizes women, limiting their full citizenship rights. This is echoed in research highlighting the political invisibility of caregiving labor, which reinforces systemic barriers to women's rights (Funk et al., 2024, p. 2). Consequently, women with caregiving responsibilities are burdened with obligations rather than rights, face uncertainties about the future, and, in the absence of adequate social policies, some express distressing fears about what will happen to their dependents.

> *I am very afraid of who will look after her if I die. If her sister takes care of her, will the brother-in-law accept this? How will they behave? How will the State take care of her if the State takes over her care? May God take her first and then me (P13, 58, Secondary school, Housewife).*
>
> *I pray, 'Lord, don't leave my child behind. No one can take care of him if something happens to me. (P17, 66, Primary school, Housewife).*
>
> *We are able to cope for now, but when we are not able to, what will happen when we get older? We will do as much as we can; I have no idea what will happen beyond that … we are faced with a deadlock. We know that the State takes over when the parents die. Is it according to some sort of order, or what? We do not know exactly how the State determines this (P2, 50, University, Retired).*

Participants' views on caregiving are shaped by factors such as education, socialization with others in similar situations, and awareness. While some frame caregiving as a personal, conscience-driven responsibility, others approach it from the perspective of welfare, citizenship, and rights. Despite these differences, they share a common belief that current care policies are inadequate and require reform to better address caregivers' well-being.

The caregiving burden is further exacerbated by systemic inequities. Underfunded public care services, as noted by Duncan et al. (2020) and Fast et al., (2024), intensify the crisis, leaving women to take on more responsibilities without sufficient support. Financial constraints, particularly among those in poverty, add to caregivers' stress, revealing the need for policy interventions (Cheshire-Allen & Calder, 2022). The sustainability of both formal and informal care systems is jeopardized by growing dependence on unpaid labor. Humphries (2022) warns that the instability of the family care sector directly endangers the formal care system, which heavily relies on family caregivers.

These care-related disparities reinforce social inequalities, making policy interventions critical to reducing caregiver burnout and ensuring equitable distribution of labor. Citizenship and civil society development must be understood within "the dynamic relationships between region, state, and global society in the modern world" (Isin & Turner, 2002, p. 8). In the global discourse on labor and rights, women increasingly advocate for legal protections and engage in the women's movement. As emphasized by Çakır (2014) and Nash (2014), achieving a democratic society requires the full participation of women [caregivers] in decision-making, social security inclusion, and formal recognition of their labor.

Women caring for disabled children navigate a complex intersection of pity, sanctification, and exclusion, engaging in a "struggle for belonging" (McLaughlin et al., 2008, p. 130) as they challenge societal norms. Their perspectives on caregiving, shaped by their education, socialization, and awareness, reflect varying frames of caregiving. Despite these differences, they all agree that policies must be reformed to better consider caregivers' well-being.

However, caregiving responsibilities significantly shape women's access to social and economic rights, often resulting in financial precarity. This constraint limits their participation in paid work and is compounded by the broader structural invisibility of caregiving in public policy. To address these issues, there is a pressing need for legislative frameworks that recognize care as a collective responsibility rather than an individual one.

Insufficiently funded public care services exacerbate the crisis, forcing women to assume additional responsibilities without adequate support (Fast et al., 2024, p. 236). As Hess et al. (2022, p.1) argue, “increasing societal investments in care and strengthening support for working adults …would affirm the value of unpaid household and care work and contribute to the well-being of households, communities, and societies.” However, caregiving remains structurally invisible in public policy, restricting women’s access to social and economic rights and reinforcing financial precarity. Legislative recognition of care as a collective, rather than individual, responsibility is essential.

In response to this lack of recognition, caregivers have mobilized to advocate for systemic change. The study found that, through their efforts to engage with institutions, a care-oriented social movement emerged. As Coffey et al. (2020, p. 18) also note, this process should involve collaboration with women’s rights groups, feminist economists, and civil society experts, alongside increased funding for organizations that support caregivers’ participation in decision-making. Such “activism can also help some home-based family carers maintain social participation and mitigate isolation, particularly in cultures with strong traditional gender roles” (Heng-Hao, 2009 in Funk & Hounslow, 2021, p. 457). This movement has empowered women caregivers and positively contributed to their psycho-social well-being, reinforcing the necessity of recognizing caregiving as a political and public issue requiring systemic change.

4. Conclusion

Informal care work, predominantly performed by women, remains an undervalued yet essential form of labor shaped by entrenched social policies that reinforce traditional gender norms. This study builds on existing research by examining the intersection of disability care, gendered labor divisions, and the social isolation experienced by caregivers in Turkish households. Like previous studies, this research draws attention to the burdens of gendered care work; however, it also adopts a more holistic perspective by considering the distinct challenges faced by caregivers of disabled children and the broader socio-economic implications of their labor.

The findings indicate that caregiving responsibilities, in the absence of institutional support, contribute to economic precarity and limit caregivers’ access to fundamental rights. Participants report experiencing emotional exhaustion, chronic sleep deprivation, declining health, and restricted opportunities for personal and professional development. Moreover, these dual pressures—care labor and financial instability—not only affect caregivers but also have far-reaching consequences for the well-being of disabled individuals. By situating caregiving within a structural rather than purely individual framework, this study stresses the need for policies that recognize care work as integral to both economic and social systems.

Within this broader discussion, the Turkish home carer’s allowance emerges as one of the key aspects of the analysis. While this financial assistance provides essential economic relief, it may also reinforce traditional caregiving roles and contribute to social isolation. Moreover, in the absence of complementary measures—such as institutional support, respite care services, and spousal involvement programs—the allowance serves as a temporary remedy rather than a comprehensive solution. The findings suggest that a more holistic caregiving policy framework is needed, one that integrates social security rights, accessible care services, and legal protections to address the vulnerabilities faced by caregivers. Additionally, the study reveals the importance of collective advocacy in strengthening support networks and influencing policy reforms, highlighting the potential of grassroots mobilization in shaping more inclusive caregiving policies

Beyond its policy implications, this research engages with feminist care theory and citizenship studies by framing informal caregiving as both a form of labor and a determinant of social inclusion. It extends discussions on fragile citizenship (Isin & Turner, 2002) by illustrating how caregiving responsibilities can systematically constrain women's full participation in economic and political life. By integrating lived experiences with structural analysis, this study contributes to a growing body of literature that challenges perspectives that reduce caregiving to an individual obligation rather than a shared social responsibility.

Ultimately, this study emphasizes the importance of reframing caregiving within a rights-based approach that acknowledges care labor as fundamental to society. A shift from an assistance-based model to a citizenship-oriented framework would help ensure that caregivers receive the economic security, social protections, and institutional support necessary to sustain both their well-being and that of those they care for. Addressing these systemic challenges is not only a matter of gender equity but also a crucial step toward fostering a more inclusive and just society.

Acknowledgements

I would like to express my heartfelt thanks to all the carers of disabled children who shared their valuable thoughts and feelings with me in this research.

Conflict of interest

The author declares that there is no conflict of interest related to this study.

Research and publication ethics statement

This article represents original research based on original data. It has not been previously published nor submitted for publication elsewhere. The author has adhered to ethical principles and guidelines throughout the entire research process.

The research was approved by the Ethics Committee of the Faculty of Social and Human Sciences at Bandırma Onyedi Eylül University (Approval No: 2022-4) on 01 April 2022.

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