



A STUDY ON FAMILY CAREGIVERS IN THE CANARY ISLANDS

THE RIGHT TO CARE AND BE CARED FOR



Report promoted by:



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PRESENTATION

“Women who fight in the war of care, especially the ones who fight without modern weapons; women who make people and institutions uncomfortable and accountable with their rebellious attitude; women who encourage other women, demanding the right to live with dignity.”

COMMITTEE OF EXPERT WOMEN CAREGIVERS OF ACUFADE



1. PRESENTATION

When we refer to caregivers in our region, some of the most common names are María, Nieves, Pino, or Candelaria –mostly women.

These “housewives” and “traditional” women were brought up with the explicit and implicit obligation to care for their relatives. This duty was enforced by customs, culture, traditions, and government structures, who know that guilt, the devastating feeling that appears when they “do not live up to the expectations” is their most potent ally. Women are taught that caregiving is their responsibility; that it is, fundamentally, “a woman’s thing.”

Care work and sexism are tightly intertwined. Although care work implies undertaking all the activities necessary for psychological, physical, emotional, and social welfare, these actions usually occur within the private domain, traditionally restricted to women. While there are indeed men caregivers, their numbers are fewer. Undeniably, men’s participation in reproductive labor is very low, as men’s traditional and current focus has been on the public domain.

If we direct our attention to the Canary Islands and ask ourselves: “Who are the caregivers?”, “Under which circumstances do they work?”, “What is their profile?”, “What is the connection between caregivers and dependent individuals?”, “What resources do they have?” and “What are the personal consequences for caregivers?”, we cannot find the answer. Until now, nobody has delved into describing the reality of women caregivers.

This is the very reason why we initiated this rigorous research. This project has been made possible thanks to the great effort and collaboration of numerous individuals and institutions and, notably, our Support Network, which makes us genuinely proud. With its support, we have found the courage to undertake challenges of this magnitude.



1. PRESENTATION

We hope this study will pave the way to conduct a much-needed analysis of family caregivers in the Canary Islands, allowing us to paint a more precise picture of their reality. Furthermore, and most importantly, we aim to raise awareness about the pressing necessity to transition towards a society that prioritizes welfare, built from the recognition of everyone's right to care and be cared for. Nonetheless, such an aspiration will not be achievable until we address the issue of enslaved and unpaid labor. It will not be attainable until we fully protect and guarantee the fundamental right to life, and it will not be possible until we acknowledge the importance of care, which is essential for all of us to lead more fulfilling lives.

ACUFADE's Head Department



November 5th, 2021



INTRODUCTION

“The support of a group of women caregivers that feel and experience the same things I do has made me feel alive again”

-CAREGIVER OF EL TREN DE LA FELICIDAD



2. INTRODUCTION

The analysis of the structural nature of care work, as well as the circumstances affecting caregivers, who are often –and incorrectly– referred to as “informal caregivers” must be addressed from a systemic perspective, considering the legal, political, economic, and social framework surrounding the situation of caregivers, as well as the interaction between these factors. This is the only way to properly understand the continuous limitations that caregivers face despite the existence of available resources.

In that regard, and strictly from a legal perspective, it can be confirmed that there is indeed financial support intended for those who care for dependent people. In fact, in article 18 of the Act 39/2006 of 14 December for Promotion of Personal Autonomy and Assistance for Persons in a Situation of Dependency (SAAD, by its Spanish acronym), a specific subsidy is included, which determines that exceptionally and when the beneficiary person is being cared for by their family environment and if the conditions established in the article 14.4 are met, an allowance will be given to cover the costs of family care.

Nevertheless, this provision conflicts with the lack of resources since, although the conditions to receive this allowance are contemplated in the Resolution of 13 July 2012, which determines the maximum amount of 387.64€ per month for Third-Degree dependency (Great dependency), the non-professional caregiver must have worked as a caregiver during the year before the submission of the application. As a result, there is a delay of up to 927 days in processing this type of allowance.

The breach of legally required deadlines, the bureaucratic maze, and the permanent decrease of the financial endowment aimed at complying with the information laid down in the Dependency Act are the three main obstacles to the recognition and implementation of the rights of caregivers. The law meant to protect the rights of individuals in situations of dependency as well as their care environment did not effectively achieve implementation, resulting in the deterioration of the assistance provided to dependent people and caregivers, who find themselves on waiting lists every year.

2. INTRODUCTION

All these issues remain invisible and have not been tackled in the political agendas. Furthermore, actions aimed at protecting the fundamental rights of caregivers have not been implemented either; that is why, despite the existence of a legal framework, care work remains today —as it has been considered historically— a duty assigned to women, alluding to cultural and moral claims rooted in our society. In this regard, the report “Time to care. Unpaid and underpaid care work and the global inequality crisis” (2020), published by Oxfam Intermón, points out that: “Nowhere in the world do men do as much care work as women. Globally, women undertake more than three-quarters of all unpaid care work, and they make up two-thirds of the paid care workforce”.

Furthermore, regarding the invisibilization and lack of recognition of care work, the report highlighted that “when unpaid and paid care work is taken together, globally women do the equivalent of six weeks a year of full-time work more than men. It is not that women do not work, it is that they work too much, and the majority of their work is unpaid, unrecognized, and invisible”.

This reality is often perceived by institutions as a private and personal problem that does not need to be addressed. Nonetheless, many women caregivers give up their place in the labor market to care for dependent people full-time. While doing this, they have to manage household chores simultaneously. This and the non-recognition of care work are the cornerstones of the welfare state and the financial structure. This phenomenon occurs within a fundamentally masculine hegemonic space, where the system perpetuates itself through historical violence, which survives to this day, excluding and dehumanizing family caregivers and devaluing their lives.

2. INTRODUCTION

“We fight for the Right to live with dignity”

- CAREGIVER OF EL TREN DE LA FELICIDAD

What has been stated refers to a global context, and not necessarily to our immediate environment. This is due to the lack of specific research in the Canary Islands, which is essential to gain an in-depth understanding of the reality surrounding the invisibilized community of family caregivers.

This is, particularly, the reason why ACUFADE has decided to undertake this research in an attempt to shed some light on the dark context of caregivers in the Canary Islands. Their situation has often been undervalued throughout history, primarily because it is associated with a feminine nature, which needs to be made visible to give voice to Canarian caregivers.

Thus, this paper is a groundbreaking study in our region. The main goal of this research is to explore and describe the current situation of family caregivers that care for individuals in situations of dependency in the Canary Islands from a multidimensional approach that includes a detailed analysis of the different areas of their lives (personal, social, health, work life, family setting, etc.), as well as the various contexts where care work takes place (intrapersonal, interpersonal, formal and informal support network, etc.). The ultimate purpose of this study is to propose new suggestions and tools that help improve the quality of life of caregivers. In doing so, the quality of the care provided will also improve. To achieve this goal, some specific objectives have been established, meeting both a strategic interest and a practical need in the deployment of future actions:

2. INTRODUCTION

- 1.** Define the sociodemographic and economic profile of family caregivers.
- 2.** Describe the care work circumstances of caregivers in relation to the individuals they care for, as well as their needs and support resources.
- 3.** Measure the relevance and use of resources exclusively intended for caregivers.
- 4.** Analyze the perception of the impact of care work on the quality of life of caregivers, as well as its consequences on different areas of their daily lives, their health, and due to the pandemic.
- 5.** Gain insight into caregivers' perspectives on the social recognition of care work and their views on potential measures aimed at improving their quality of life and work conditions.

METHODOLOGY

“Being a caregiver, devoting yourself body and soul to care, 24 hours a day, 365 days a year.”

- CAREGIVER FROM THE CANARY ISLANDS



3. METHODOLOGY

To portray the reality of family caregivers in Canarias, this research adopts a quantitative methodology using sampling surveys. The study took place between the months of February and October 2021, as indicated in the following table:

Table 1: Research process and timeframe

Steps	Date (2021)
Presentation of the draft	February - March
Review of bibliography and secondary sources	April
Planning -Identify concepts that need to be measured -Define and delimitate the universe of the study -Design the sample -Establish the instrument for data collection -Select and train the fieldwork team -Form a network of collaborating institutions	April - May
Field data collection	June - August
Statistic exploitation and data analysis	September - October
Write the results report	October

The technical aspects of this process are detailed below.

3.1. UNIVERSE OF THE STUDY

The universe of the study is the following:

- Demographic area: the Canary Islands.
- Universe: people aged 18 and older, working (until December 2019 or up to the present day) as caregivers of individuals in situations of dependency (which is a permanent state where dependent individuals, due to different reasons like age, illness, or disability, need assistance or help to carry out daily tasks) in any degree, officially recognized or not.

3. METHODOLOGY

3.1. UNIVERSE OF THE STUDY

This research focuses on people who provide care for dependent individuals, whether they perform this task alone or in collaboration with other people. Moreover, family caregivers are also included in the universe of the study, regardless of whether they live with the dependent individual they care for.

It is important to mention that this research does not target professional caregivers, nor individuals who seek assistance from care centers for their dependent family members.

3.2. SAMPLE

Table 2: Sample distribution in each island

ISLANDS	Absolute fr.	%
Tenerife	265	39,4
Gran Canaria	242	36
La Palma	21	3,1
El Hierro	21	3,1
La Gomera	26	3,9
Lanzarote	46	6,8
Fuerteventura	51	7,6

Sample size:

672 valid interviews. The sample includes caregivers from the 88 towns that make up the Canary Islands. The participation rate in each island and province is shown below.

Sample allocation:

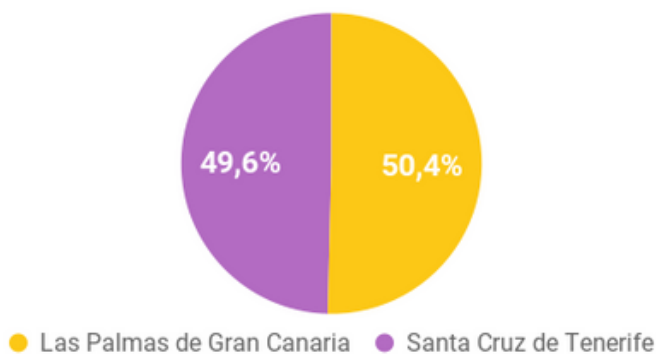
Proportional allocation.

Data collection method:

Computer-assisted telephone interviewing.

The chosen instrument for data collection was a structured interview, including a list of 83 questions with an average duration of 40 minutes. A pilot test of 12 telephone interviews was conducted to test the validity of the research instrument.

Graph 1: Province



3. METHODOLOGY

3.2. SAMPLE

Several sessions were conducted to select and assemble the research team. A written guide was provided to ensure the effective management of the survey process and to furnish the necessary training concerning caregiver interactions. Additionally, a supervision protocol was established to guarantee the quality of the resulting database. This protocol included validating an average of 25% of the interviews conducted by each team member, along with weekly monitoring of the database.

Sampling techniques and procedure:

Non-probabilistic snowball sampling, assisted by simple random sampling.

Due to the absence of an official registry of Canarian caregivers and limited available information in our region regarding the universe of the study, as well as time and cost constraints, it has been necessary to combine these two sampling methods to reach family caregivers across the seven Canary Islands.

Snowball sampling is a sampling technique in which participants are recruited by other participants to reach samples that might otherwise be difficult to identify, as is the case of this research. In addition to the participant population, databases of caregivers provided by the support network of collaborating entities and participants referred by professionals were consulted.

In instances where the samples obtained through this technique proved insufficient to achieve an accurate representation of the population in certain islands, simple random sampling was employed by selecting random telephone numbers from the population registered in the telephone directory of each respective area where this technique was applied.

3. METHODOLOGY

3.2. SAMPLE

The following chart displays the sampling technique –or their combination– employed on each island:

Table 3: Sampling techniques on each island

ISLANDS	Sampling technique
Tenerife	Snowball
Gran Canaria	Snowball Simple random
La Palma	Snowball Simple random
El Hierro	Snowball
La Gomera	Snowball
Lanzarote	Snowball Simple random
Fuerteventura	Snowball

The chart below lists the institutions that participated in snowball sampling on each island:

Table 4: Institutions collaborating on snowball sampling

ISLANDS	Institution
Tenerife	ACUFADE Volunteering Institutions of Canarias Platform Federation ATELSAM Community Liaison Nursing
Gran Canaria	ACUIGRANCA Community Liaison Nursing ADDISUR
El Hierro	RED CROSS Community Liaison Nursing Local gov. of Valverde
La Gomera	RED CROSS Social Services of the local gov. of La Gomera
Fuerteventura	AFFA
Lanzarote	Isla de los Volcanes Day Care Centre

3. METHODOLOGY

3.2. SAMPLE

Sampling procedure:

The margin of error associated with 672 interviews is ± 3.85 for a confidence level of 95.5%, and in the case of maximum uncertainty ($p=q=0,5$), for an estimated universe of 94.743, in relation to the total results in the Canary Islands.

The estimation of the universe of analysis (94.743) has been based on the applications and resolutions of the Dependency Act in the Canary Islands, calculated from the data of May 2021.

3.3. STATISTIC EXPLOITATION AND DATA ANALYSIS

Statistical analysis software IBM SPSS was employed to manage the resulting database. During this phase, the following actions were conducted:

- Survey data cleaning.
- Coding of open-ended questions.
- Descriptive statistical analysis.
- Contrasts analysis. In this step, adjusted standardized residuals were used for percentages, while ANOVA was employed for the analysis of means. This report only includes those analyses that reveal significant differences at a statistical level, with the ones of positive order being highlighted through graphs and table shading.

RESULTS

“Have you ever stopped to think about the actual cost of caring for our relatives?”

- CAREGIVER FROM THE CANARY ISLANDS



4.1. SOCIODEMOGRAPHIC AND ECONOMIC PROFILE OF CAREGIVERS



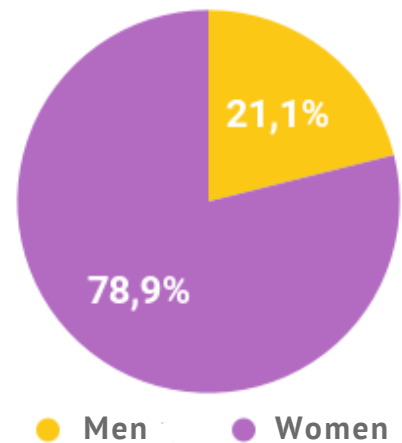
78.9% of caregivers are women.

65.6% of caregivers are between 45 and 65 years old, with an average age of 54 years. The majority of caregivers are married (59.3%), while 29.6% are single. In terms of their level of education, 31.3% have completed secondary education, and 23.4% have lower studies.

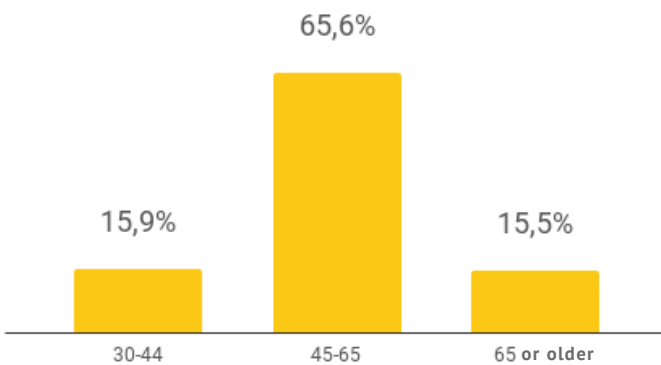
57.9% of them work exclusively as family caregivers, which includes homemakers, retirees, unemployed, and/or in situations of incapacity for work.

42.1% combine caregiving responsibilities with paid employment or self-employment.

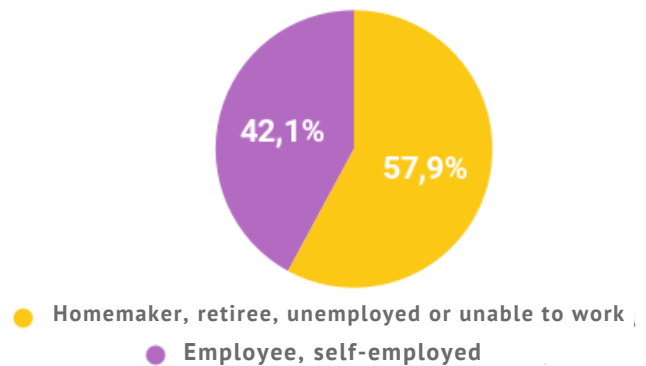
Graph 2: Gender



Graph 3: Age

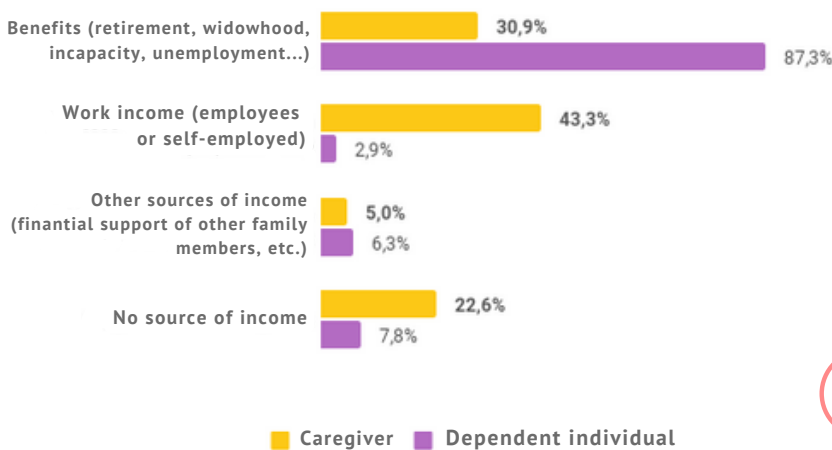


Graph 4: Current employment status



4.1. SOCIODEMOGRAPHIC AND ECONOMIC PROFILE OF CAREGIVERS

Graph 5: Source of income



72.9% of caregivers live with 2 to 4 people.

The most common relationships are partners (67.9%), offspring (children / grandchildren) (60.2%) and parents (37.6%).

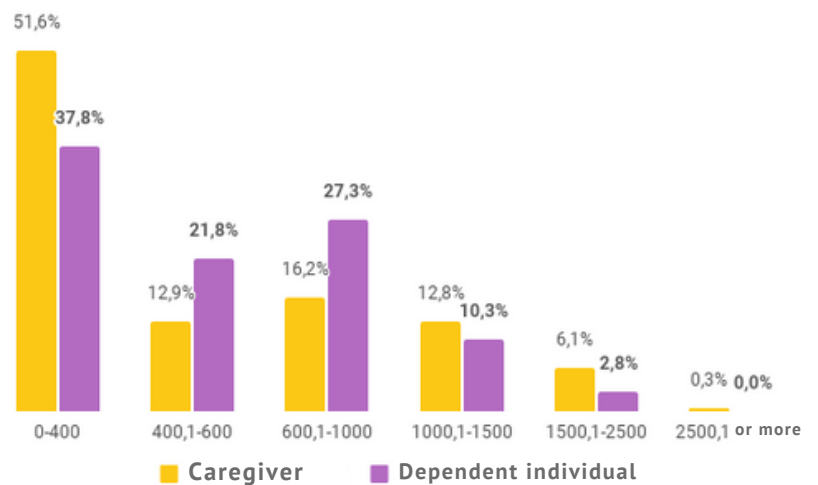
51.6% of caregivers receive 400 euros or less monthly. As for dependent individuals, 59.6% receive 600 euros or less.

In terms of the source of their incomes:

Caregivers: 37.4% of their income comes from paid employment or self-employment, 23.9% comes from various benefits (retirement, widowhood, incapacity, unemployment, etc.) and 19.5% have no income at all.

Dependent individuals: 73% of their income comes from financial benefits, while 6.8% have no income at all.

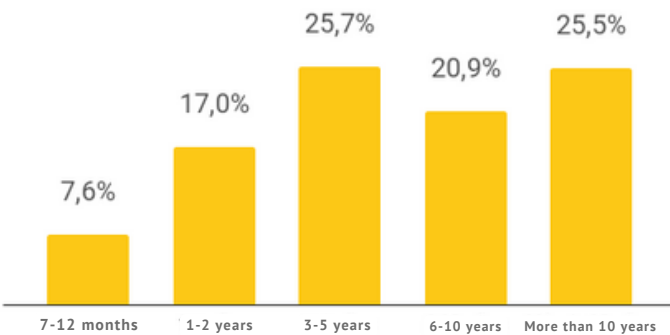
Graph 6: Monthly income (€)



4.2. CARE WORK (NEEDS AND RESOURCES)

4.2.1. Dedication to caregiving

Graph 7: Time devoted to caregiving



46.4% of caregivers have been performing this task for more than 6 years, with more than half (25.5%) providing care for more than 10 years.

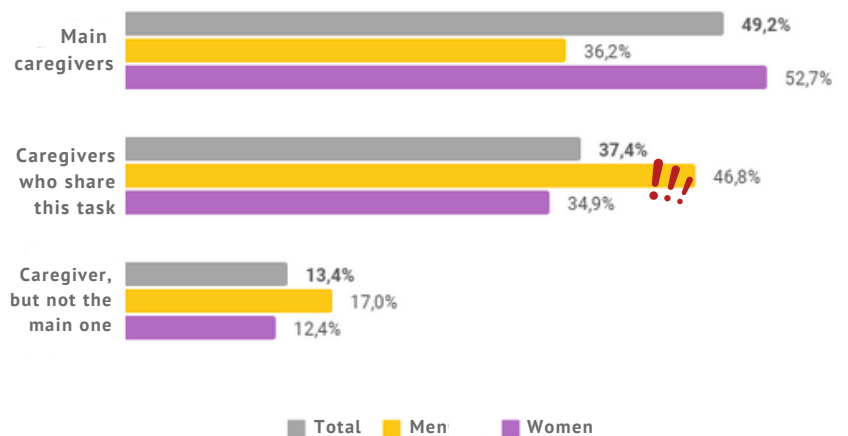
While the majority of them (81.5%) care for a single dependent individual, more than 15% of women caregivers care for 2 or more dependent individuals.

Among interviewed caregivers, 49.2% stated they were the main caregivers, meaning they were solely responsible for assisting dependent individuals, while 50.8% shared this task with other people. Out of the total number of women, 86.7% were main caregivers, either solely responsible for caregiving responsibilities or sharing this task with others. Additionally, among the group of main caregivers, women (52.7%) outnumber men (36.2%).

However, among the group of caregivers who share their task, the number of men (46.8%) significantly exceeds that of women (34.9%).

In conclusion, women caregivers are more likely to be solely responsible for undertaking care work compared to men, while men caregivers tend to share this task with other women.

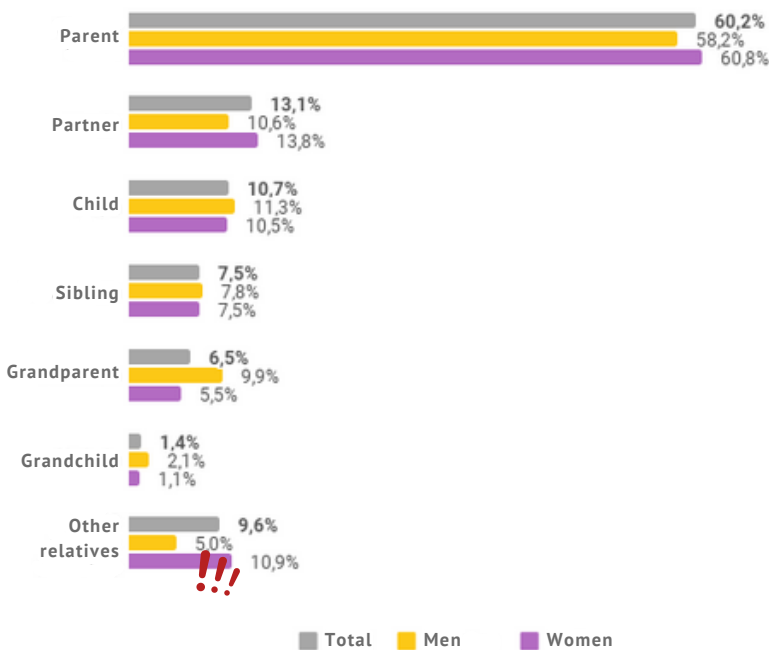
Graph 8: Dedication to caregiving by gender



4.2. CARE WORK (NEEDS AND RESOURCES)

4.2.1. Dedication to caregiving

Graph 9: Relationship with the dependent individual by gender

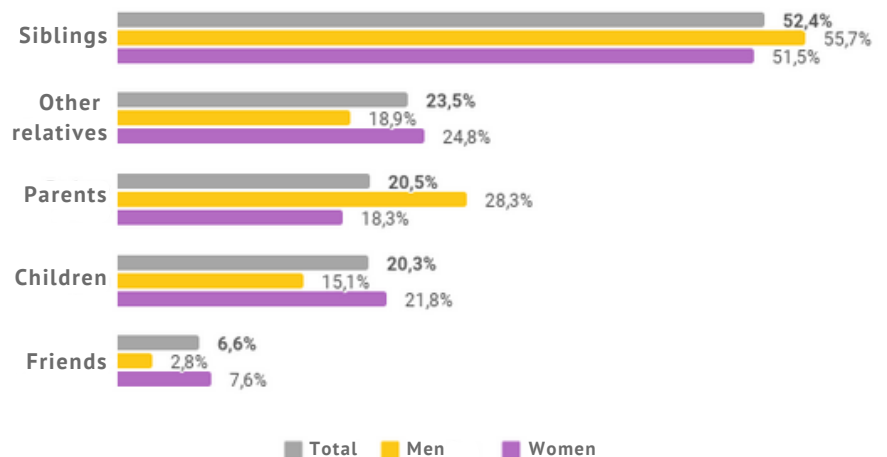


Women are significantly more likely than men to care for their in-laws (sister/brother-in-law, daughter/son-in-law, parents-in-law) and other family members (aunt/uncle, niece/nephew) (10.9% compared with 5% of men). Generally, women caregivers live with the dependent individual they care for (53.3%). In such cases, they either had to relocate to the domicile of the dependent individual (57.9%) or vice versa (39.4%).

Regarding the people they share caregiving responsibilities with, siblings are the most mentioned type of kinship (52.4%), followed by other relatives (23.5%) and parents (20.5%).

Men caregivers are more likely to share this task with their progenitors (28.3% compared with 18.3% of women).

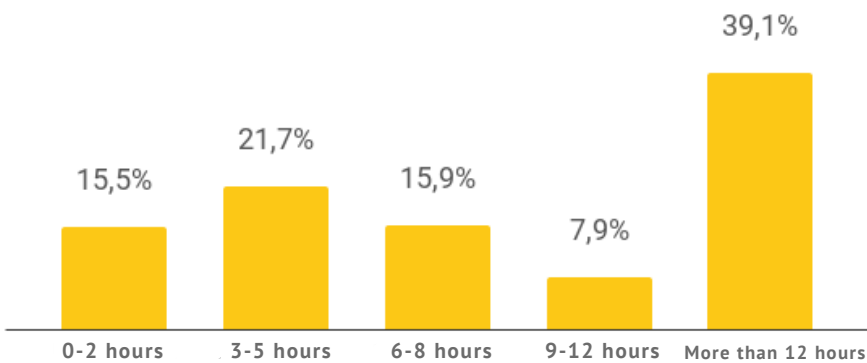
Graph 10: Relationship of the caregiver with the person they share caregiving responsibilities with, based on the caregiver's gender



4.2. CARE WORK (NEEDS AND RESOURCES)

4.2.1. Dedication to caregiving

Graph 11: Time devoted to caregiving

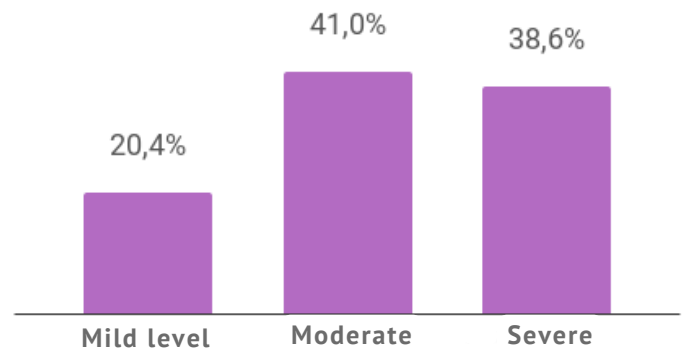


47% of caregivers reported dedicating more than a full workday (9 hours or more) to caregiving, with 39.1% spending more than 12 hours daily.

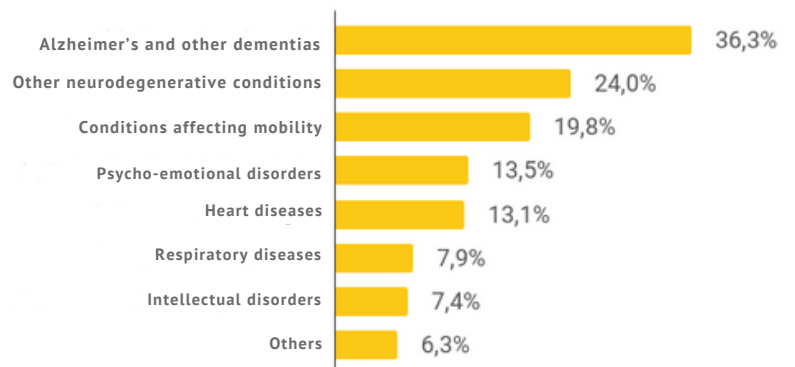
The level of dependency perceived by the caregivers of the individuals they cared for mainly corresponds to moderate (41%) and severe (38.6%) dependency.

Participants indicated they cared for many individuals with neurological diagnoses, such as Alzheimer's disease and other dementias (36.3%) and other neurodegenerative diseases (24%). This was followed by conditions affecting physical mobility, such as hemiplegia, paraplegia, dystrophy, amputations, etc. (19.8%), and psycho-emotional disorders (13.5%) like bipolar disorder, schizophrenia, and depression, among others.

Graph 12: Level of dependency



Graph 13: Main diagnosis of dependent individuals

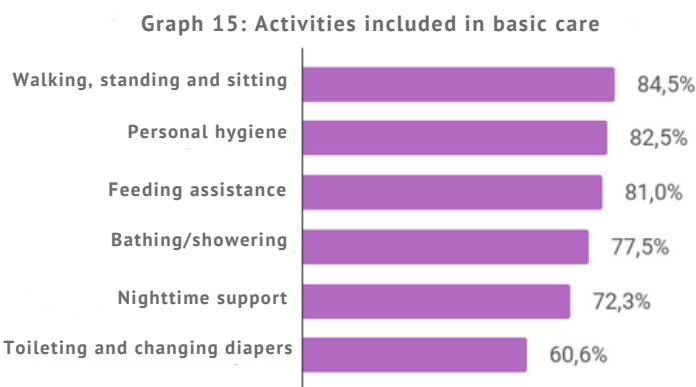
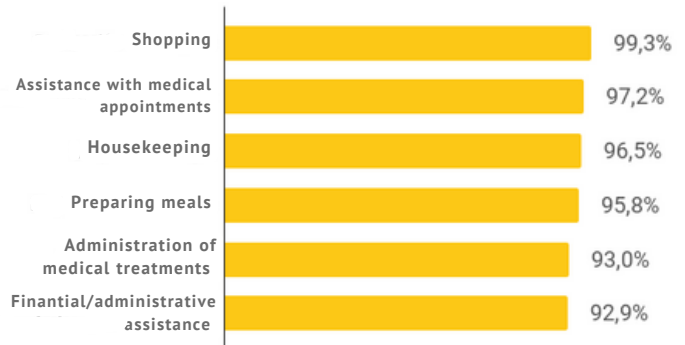


4.2. CARE WORK (NEEDS AND RESOURCES)

4.2.2. Types of care provided

The predominant type of care provided when assisting dependent individuals is instrumental care, with basic care and specialized care following in succession. Within the domain of instrumental care, the most prevalent activities include shopping (99.3%), assistance with medical appointments (97.2%), housekeeping (96.5%), and preparing meals (95.8%).

Graph 14: Activities included in instrumental care



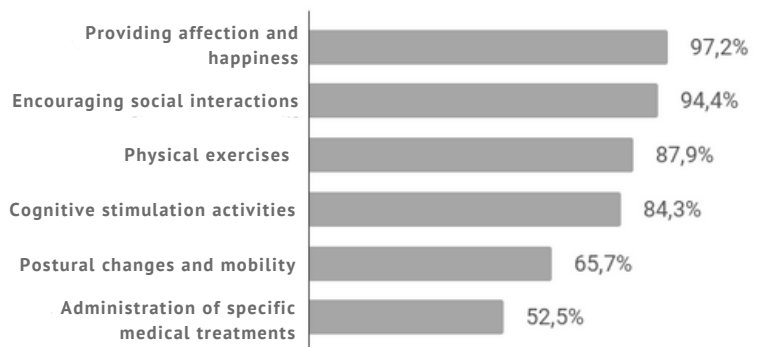
When it comes to basic care activities, the most common ones include those related to mobility (walking, standing, and sitting) (84.5%), personal hygiene (82.5%), and bathing/showering (77.5%).

As for specialized care, the most frequent activities are providing affection and happiness (97.2%), encouraging social interactions (94.4%), and physical (87.9%) or cognitive (84.3%) stimulation.

Direct care is provided in 90.6% of cases, while it is supervised in 9.4% of instances.

Women devote significantly more time to performing instrumental and basic tasks.

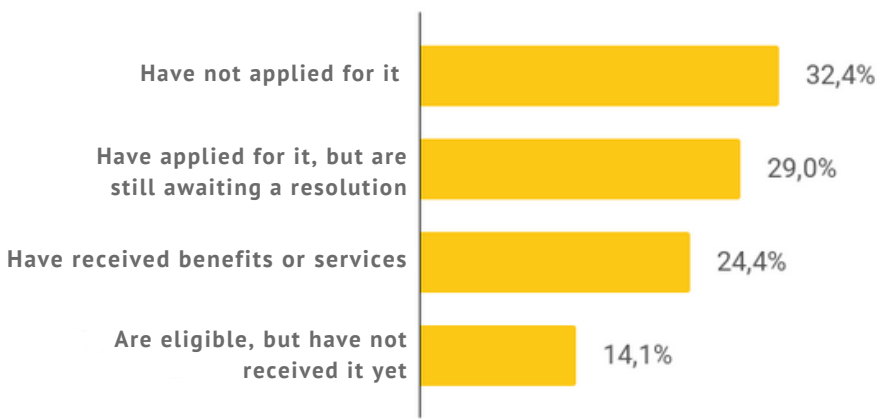
Graph 16: Activities included in specialized care



4.2. CARE WORK (NEEDS AND RESOURCES)

4.2.3. Resources for the care of dependent individuals

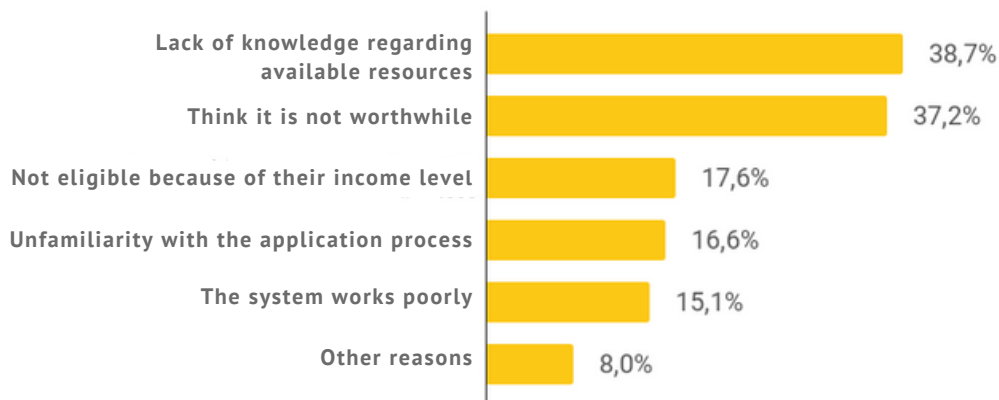
Graph 17: Current situation regarding benefits provided by the Dependency Act



Most dependent individuals assisted by family caregivers (75.5%) do not receive any kind of benefit or service related to the Dependency Act. Of those who have applied for this benefit, only 14.1% are eligible but have not received it yet, while 32.4% have not applied for it at all.

The lack of knowledge regarding access to the rights designed to support them (45.3%), especially concerning both the different types of benefits and resources available (38.7%) and the steps to follow during the application process (16.6%), besides the perception that the process may not be worthwhile (37.2%) are some of the main reasons why dependent individuals refrain from applying for these financial benefits.

Graph 18: Reasons why individuals do not apply for the Dependency Act



4.2. CARE WORK (NEEDS AND RESOURCES)

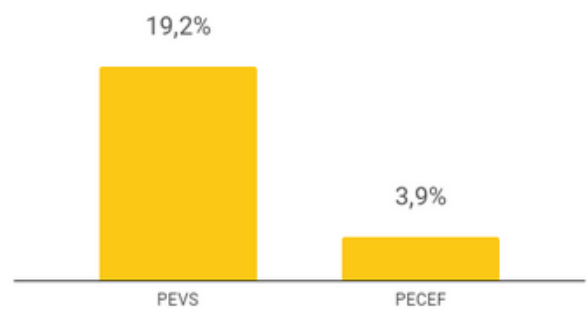
4.2.3. Resources for the care of dependent individuals

19.2% of individuals in a situation of dependency receive the Economic Benefit Linked to Service (Prestación Económica Vinculada al Servicio, or PEVS), and 3.9% of family caregivers receive the Economic Benefit for Family Care (Prestación Económica para Cuidados en el Entorno Familiar, or PECEF).

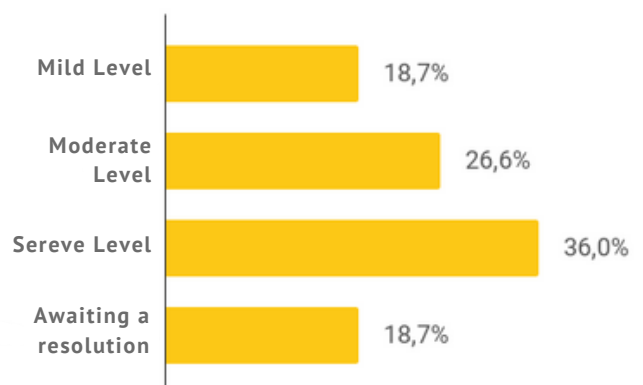
According to the official classification scale assessing the dependency levels of individuals, it is observed that 18.7% fall into the Mild Level category, 26.6% into the Moderate Level, and 36% into the Severe Level (Great Dependency). The remaining 18.7% await a resolution.

Most of the interviewed caregivers are not registered in the Social Security system as non-professional caregivers (95%), mainly due to the lack of knowledge about the pertinent procedures.

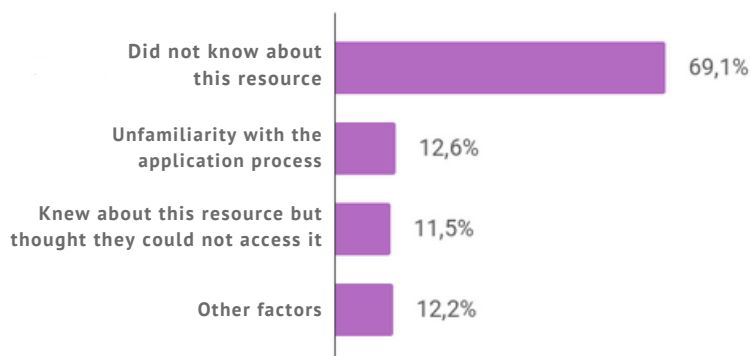
Graph 19: Type of financial benefit received



Graph 20: Levels of dependency



Graph 21: Reasons why caregivers are not registered in the Social Security system

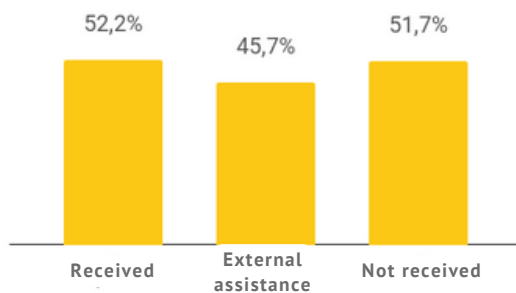


This is primarily attributed to the lack of knowledge about this resource (69.1%), while other caregivers reported unfamiliarity with the application process (12.6%). Other factors (12.5%) include incompatibilities between this resource and existing benefits, as well as the inability to apply due to different employment statuses in the Social Security system.

4.2. CARE WORK (NEEDS AND RESOURCES)

4.2.3. Resources for the care of dependent individuals

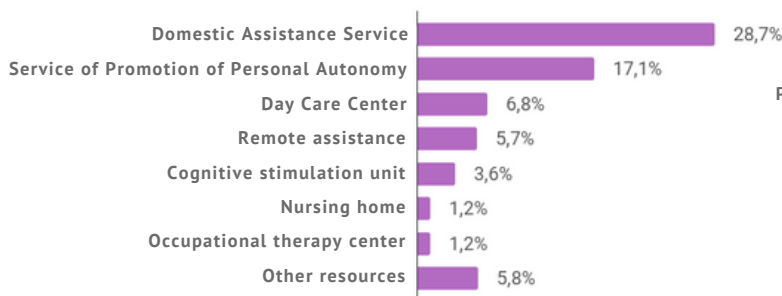
Graph 22: Current situation of resources intended for dependent individuals



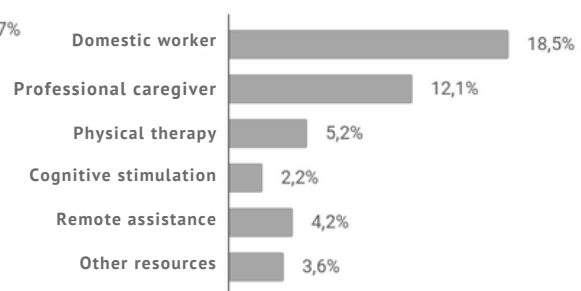
1 out of 2 dependent individuals lacks any form of support resources, whether public or private. However, 52.2% reported receiving some type of public support, while 45.7% have independently hired external assistance.

In terms of public resources, the most provided services are the Domestic Assistance Service (Servicio de Ayuda a Domicilio, or SAD) (28.7%) and the Service of Promotion of Personal Autonomy (Servicio de Promoción de la Autonomía Personal, or SPAP) (17.1%). Less than 10% of dependent individuals benefit from other public services. On the other hand, in the realm of private services, hiring domestic workers (18.5%) and professional caregivers (12.1%) are the most common options.

Graph 23: Public resources provided



Graph 24: Private resources provided



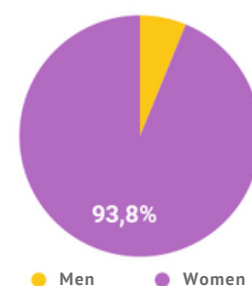
Family caregivers usually need to hire 1 or 2 professional caregivers (with an average of 1.5).



In general, these professional caregivers are predominantly women (93.8%) compared to men caregivers (6.2%).

40.4% of professional caregivers work as live-in caregivers or more than 40 hours weekly.

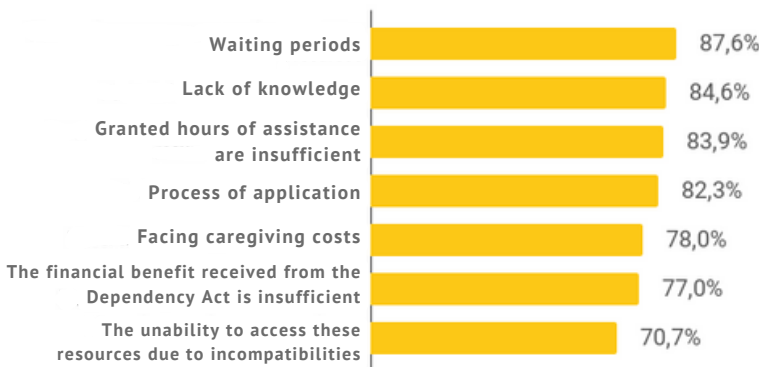
Graph 25: Professional caregivers by gender



4.2. CARE WORK (NEEDS AND RESOURCES)

4.2.3. Resources for the care of dependent individuals

Graph 26: Administrative challenges to access resources

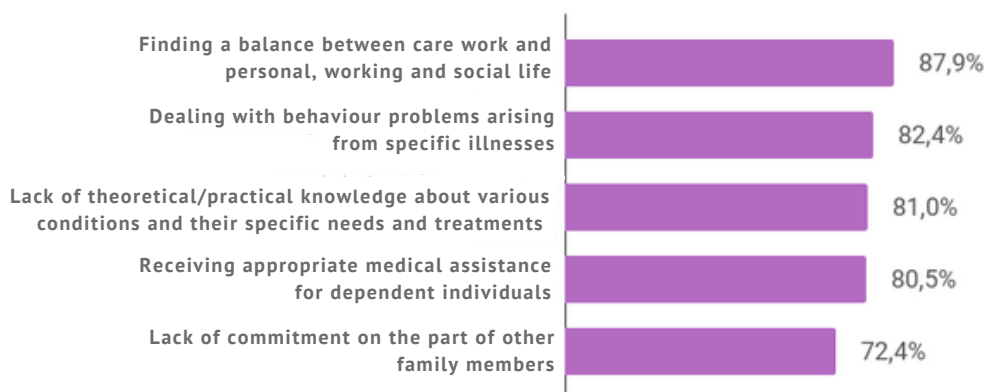


According to women caregivers, the healthcare sector (including family medicine, medical specialties, nurses, and pharmacists) is considered the most valuable source of information. In 64.1% of cases, information and counseling are provided by the Primary Health Care unit, followed by women caregivers' associations (23.8%) and local governments (20.8%).

Among the current challenges concerning public administration and resources, the most relevant obstacles are waiting periods to access services and resources (87.6%), the lack of knowledge about available resources (84.6%), the number of hours of assistance granted (83.9%) and the bureaucratic process of applying for these resources (82.3%).

Additionally, when performing caregiving tasks, caregivers encounter several primary challenges daily. These challenges include, for instance, finding a balance between care work and maintaining the quality of personal, social, and work life (87.9%), dealing with behavior problems arising from specific illnesses (82.4%), the lack of knowledge about the various conditions of dependent individuals (81%) and receiving appropriate medical assistance for dependent individuals (80.5%).

Graph 27: Challenges with daily caregiving

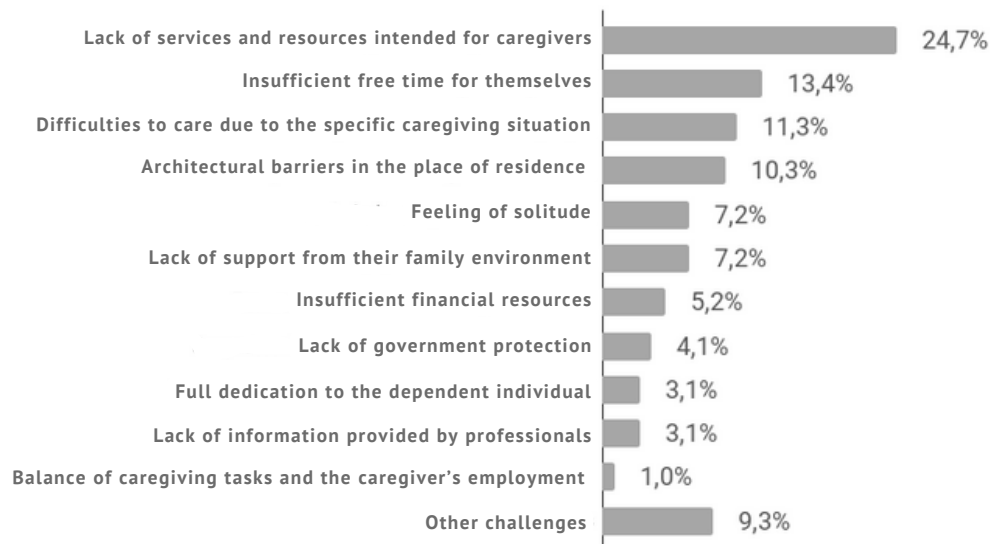


4.2. CARE WORK (NEEDS AND RESOURCES)

4.2.3. Resources for the care of dependent individuals

Among interviewed family caregivers, 83% declared the need for support services to help them cope with their daily responsibilities. They suggested specific training to improve the quality of the care provided (dealing with illnesses, basic care, etc.) (36.2%), services that ease the burden of family caregivers (34.1%), emotional support (32.1%), and assistance with the application for sociosanitary resources (27.8%)

Graph 28: Additional key caregiving challenges



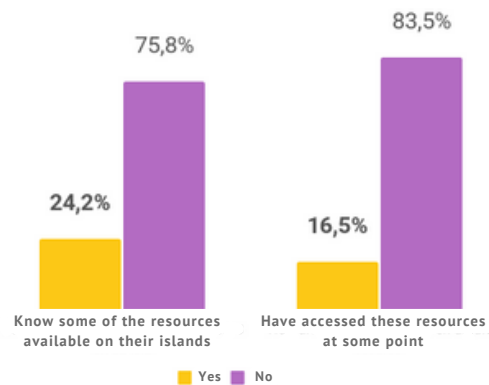
4.2. CARE WORK (NEEDS AND RESOURCES)

4.2.4. Resources exclusively intended for caregivers

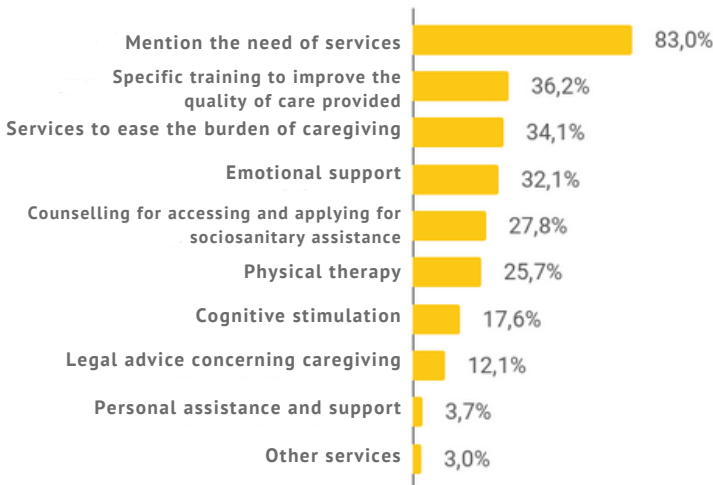
75.8% of caregivers reported being unaware of specific programs, services, and resources available to them on their islands, and **83.5%** have never participated in any of these programs.

Among caregivers who are aware, 1 out of 2 has accessed those resources at some point.

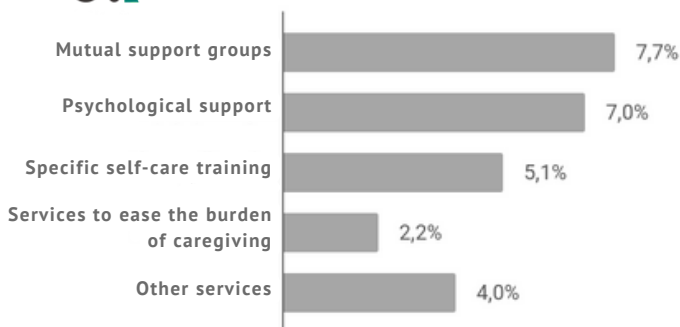
Graph 29: Awareness of resources intended for caregivers and their participation



Graph 30: Current necessary services for caregiving



Graph 31: Current received resources



Out of the total number of caregivers, 10.7% have engaged in the support network of El Tren de la Felicidad of ACUFADE, 2.4% have engaged in the groups of caregivers of the Community Liaison Nursing (or ECE, by its Spanish acronym), a nursing system based on case management, and 3.4% of caregivers have engaged in other associations and programs (ACUIGRANCA, AFFA, or projects promoted by local governments).

Currently, women caregivers primarily engage in mutual support groups (7.7%), receive psychological support (7%), and undergo specific self-care training (5.1%). Among the most frequent reasons for not participating in these programs and services, many caregivers cited a lack of time (38.5%) and a lack of information about available resources (38.3%).

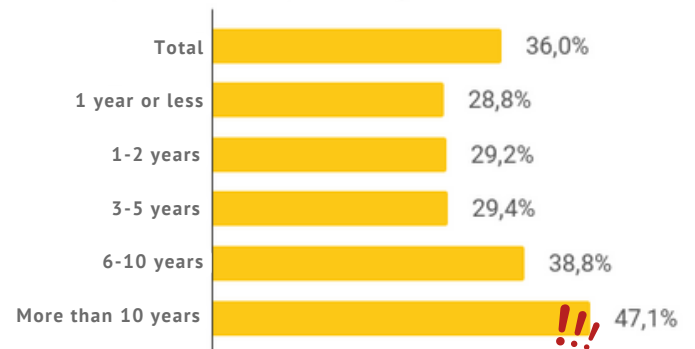
4.3. SELF-CARE AND HEALTH IMPACT OF CARE WORK

4.3.1. Self-care

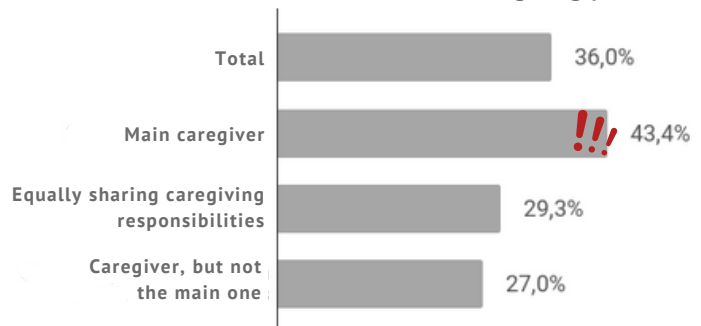
Although 74.4% of caregivers stated that self-care is quite or very important to them, 1 out of 3 caregivers spends less than 1 hour per day on self-care activities, and 45.3% dedicate 1 to 3 hours to self-care.

Caregivers who have been providing family care for more than 10 years are the ones who, at a significantly higher rate, reported they spend less than 1 hour per day on self-care (47.1%).

Graph 32: Time dedicated to caregiving based on the duration of this task

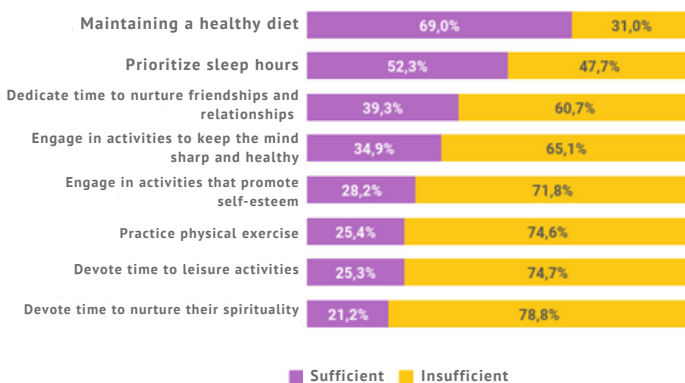


Graph 33: Caregivers that dedicate less than 1 hour to self-care based on their caregiving position



Main caregivers are, by far, the ones who spend the least time taking care of themselves, with only 1 hour or less per day.

Graph 34: Time dedicated to self-care activities



Among the self-care activities that are most frequently neglected, the top ones include spiritual care (78.8%), leisure activities (74.7%), physical exercise (74.6%), and engaging in activities that promote self-esteem (71.8%). However, maintaining a healthy diet (69%) and prioritizing sleep hours (52.3%) are the aspects of personal well-being that receive the most attention.

4.3. SELF-CARE AND HEALTH IMPACT OF CARE WORK

4.3.2. Impact on the quality of life and health consequences

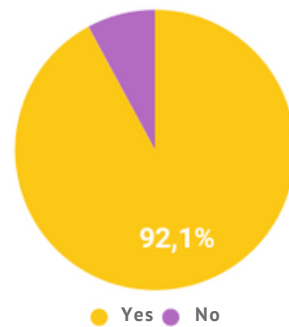
Only 21.5% of caregivers reported having the freedom to choose whether or not to perform caregiving tasks, and most of them feel obliged to undertake family care work (78.5%) due to moral, legal, or cultural reasons.

Out of the total number of caregivers, 92.1% stated that care work has been detrimental to their quality of life. This effect is most pronounced among main caregivers, with 60.5% experiencing a significant deterioration in their quality of life.

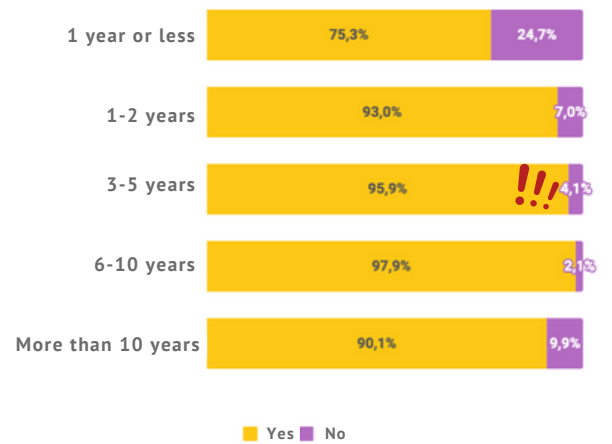
Main caregivers reported significantly higher rates of caregiving responsibilities being quite or very detrimental to their physical (52.6%) and emotional (65.5%) health.

As caregivers work for longer periods, the impact on their health becomes increasingly pronounced, particularly after the third year.

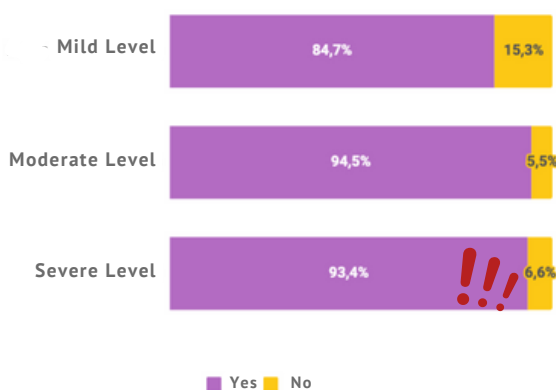
Graph 35: General impact on their quality of life



Graph 36: General impact on their quality of life based on the time they have been caregiving



Graph 37: General impact on the quality of life based on the level of dependency

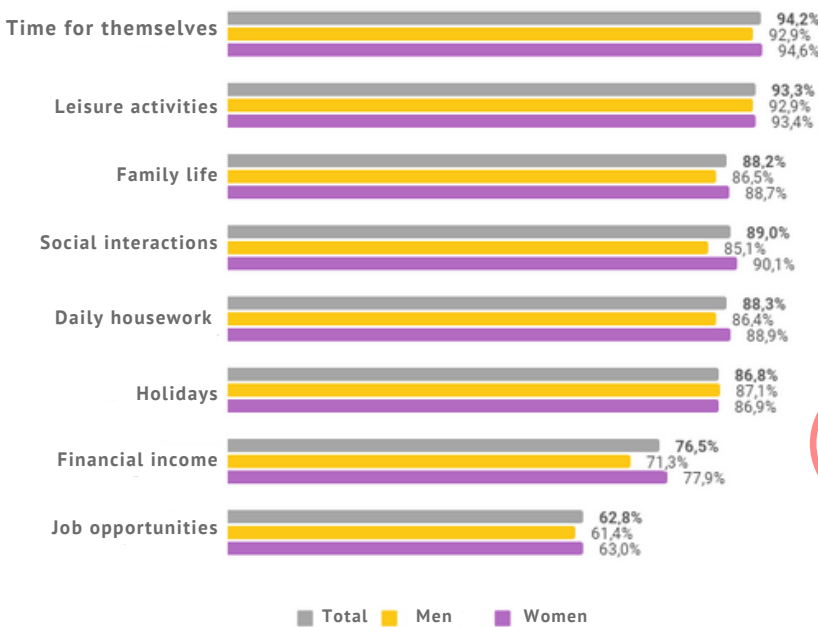


As the level of dependency of dependent individuals increases, there is a greater deterioration in the quality of life of their caregivers. In cases of moderate or severe levels of dependency, the impact is significantly worse or even severely pronounced.

4.3. SELF-CARE AND HEALTH IMPACT OF CARE WORK

4.3.2. Impact on the quality of life and health consequences

Graph 38: Life aspects affected by gender



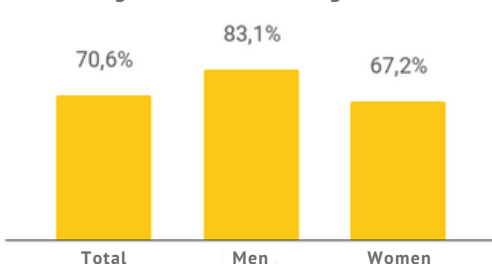
Care work significantly impacts the life of caregivers, especially those aspects related to leisure and personal time, such as having time for themselves (94.2%), engaging in leisure activities (93.3%), or doing household chores (88.3%).

Women are more affected than men in almost every aspect of their daily lives.

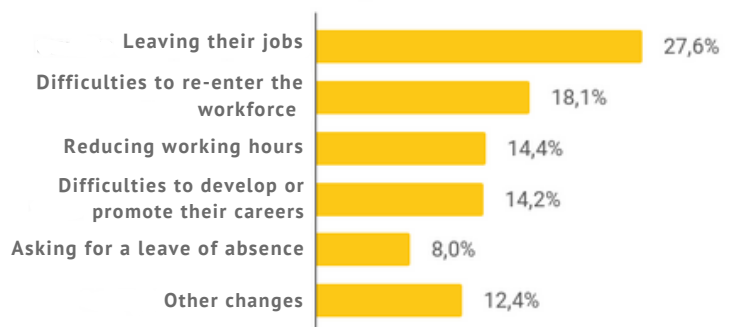
Among the individuals who experienced changes in their working life, men (83.1%) outnumber women (67.2%).

Family care work affects the working life of 70.6% of caregivers: 27.6% stated to have left their jobs, which is the most frequent outcome, and 18.1% reported having difficulties re-entering the workforce.

Graph 39: Individuals who reported specific changes in their working life



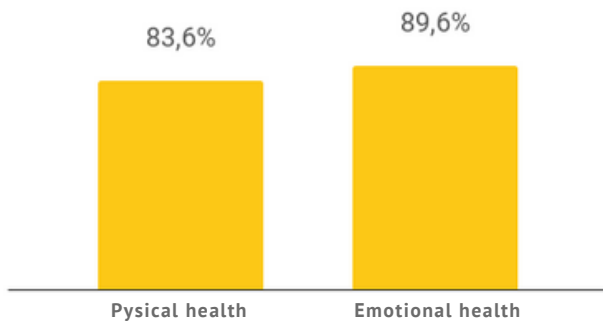
Graph 40: Changes in the working life of caregivers



4.3. SELF-CARE AND HEALTH IMPACT OF CARE WORK

4.3.2. Impact on the quality of life and health consequences

Graph 41: Impact on physical and emotional health



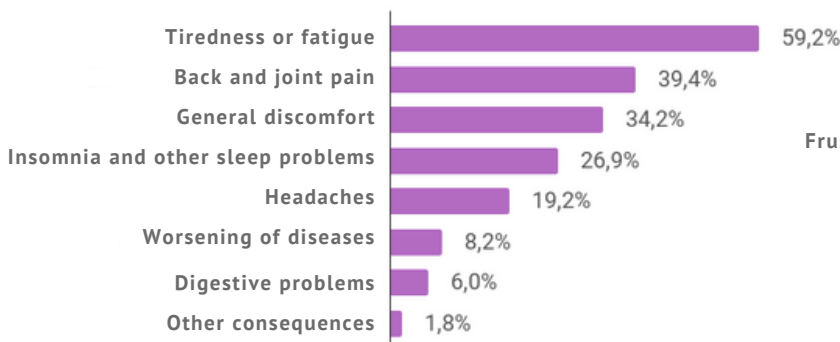
! Most caregivers claim that care work has been detrimental to their quality of life, both emotionally and physically.

The impact on the emotional health of caregivers is notably higher in those who care for individuals with severe levels of dependency.

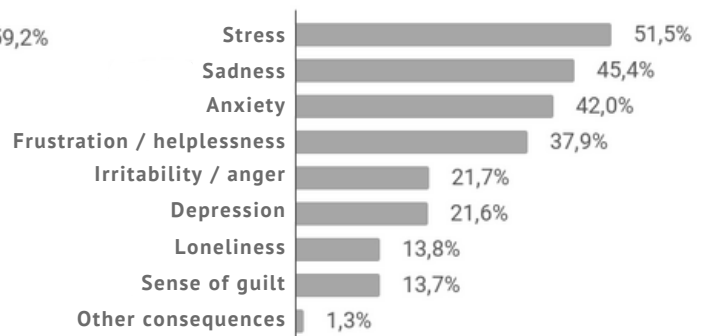
The main physical consequences are tiredness or fatigue (59.2%), followed by back and joint pain (39.4%) and general discomfort (34.2%).

Emotionally, the main effects are stress (51.5%), sadness (45.5%), and anxiety (45%). Moreover, 2 out of 10 caregivers reported suffering from depression (21.6%).

Graph 42: Main consequences on physical health



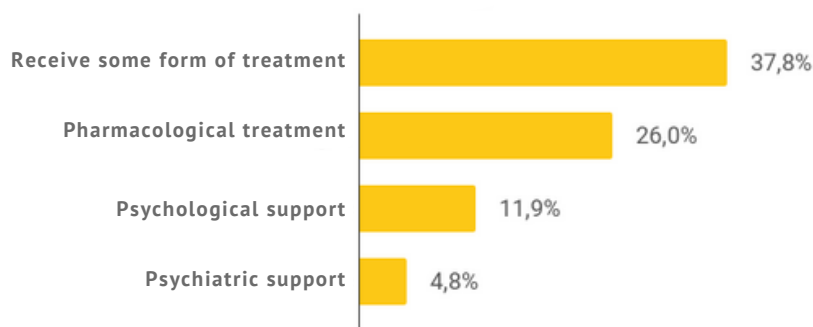
Graph 43: Main consequences on emotional health



4.3. SELF-CARE AND HEALTH IMPACT OF CARE WORK

4.3.2. Impact on the quality of life, health consequences and the effects of the coronavirus pandemic

Graph 44: Caregivers receiving specific treatment to deal with health consequences of care work and the type of treatment provided

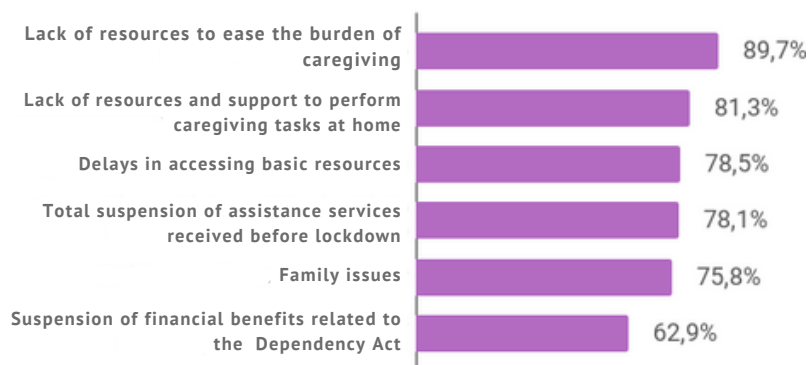


37.8% of caregivers are undergoing some form of treatment to address the physical or emotional consequences resulting from their caregiving responsibilities.

Among the types of treatment used by caregivers, 26% were pharmacological, and 11.9% were psychological. Additionally, 1 out of 2 caregivers reported seeking medical attention regularly or quite frequently.

Regarding the effects of the coronavirus pandemic, 98.5% of family caregivers reported that their circumstances have not improved since the beginning of the sanitary crisis. 1 out of 2 caregivers stated that the coronavirus pandemic has remarkably affected their quality of life, both physically (59.1%) and emotionally (53.5%).

Graph 45: Difficulties resulting from the coronavirus pandemic



Among the difficulties resulting from this situation, the most frequently mentioned ones are the lack of resources to ease the burden of caregiving (89.7%), the lack of resources and support to perform their task at home (81.3%), and delays in receiving assistance (78.5%).

4.4. CLAIMS AND ACTIONS TO IMPROVE THE SITUATION OF FAMILY CAREGIVERS

Among the demands voiced by the interviewed caregiving community, the most commonly shared concern is the perception that the available resources exclusively intended for caregivers are insufficient (81.4%), along with a feeling of vulnerability regarding the laws and rights designed to protect and support them (78.5%).

62,6% As a caregiver, I feel invisible in this society.

The value of the time and effort we put into caregiving is not acknowledged. **77,8%**

78,5% As a caregiver, I don't feel protected by the government (laws, rights, etc.).



There are not enough resources exclusively intended for caregivers.

81,4%

4.4. CLAIMS AND ACTIONS TO IMPROVE THE SITUATION OF FAMILY CAREGIVERS

The following suggestions are deemed necessary by almost 100% of caregivers:

1. **Analyzing the situation and needs of caregivers and creating a Plan of Individualized Assistance exclusive to them.** **98,5%**
2. **Establishing a public fund exclusive to assist caregivers through emotional support, physical therapy, mutual support groups, or services intended to ease the burden of caregiving.** **98,2%**
3. **Developing and implementing legislation addressed to caregivers through a National Caregiving Plan.** **98,0%**
4. **Creating a one-stop window (Ventanilla Única) where it will be possible to access information and manage all resources for caregivers quickly and efficiently.** **97,7%**
5. **Creating an identity card for caregivers that provides access to various services and benefits.** **94,7%**

Other initiatives suggested by the community of family caregivers are the following:

- Implementing a basic government benefit according to the level of dependency of the dependent individual. This resource will consist of a minimum income that will cover the actual costs of caregiving, which will finally lead to a dignified life for caregivers and dependent individuals.
- Erasing incompatibilities between financial benefits and services contained in the Dependency Act.

- **Erasing incompatibilities between contributions to the Social Security system for caring for a dependent individual, contributions made by workers, or any kind of incapacity benefit.**

4.4. CLAIMS AND ACTIONS TO IMPROVE THE SITUATION OF FAMILY CAREGIVERS

These are additional actions suggested by the community of family caregivers:

- Benefiting from a legal support service exclusive to caregivers.
- Increasing the number and efficiency of public resources intended for dependent individuals.
- Greater support from institutions regarding projects and caregiving resources that already exist, such as El tren de la Felicidad.
- Developing more accompanying protocols and care assistance protocols for emergencies and hospitalizations.
- Achieving fair and well-defined conditions for the employment of professional caregivers.
- Professionalizing and legalizing family caregiving.

“We are voices ignored by Society, claiming that We exist!”

- CAREGIVER OF EL TREN DE LA FELICIDAD

CONCLUSIONS

“We give up our own lives to care for them, because if we don’t do it, who will then?”

- CAREGIVER FROM THE CANARY ISLANDS



5. CONCLUSIONS

Family care work in the Canary Islands is primarily undertaken by women, and most of them feel obliged to perform this task.

In the Canary Islands, women constitute 78.9% of caregivers, with an average age of 54 years. The profile of this group is diverse: 1 out of 2 women is married (59.3%), has secondary education or lower (54.7%), and works exclusively as a family caregiver (57.9%), which translates to being unemployed or outside the labor market, therefore categorized as inactive.

Nevertheless, they share a common aspect: most women caregivers feel obliged to undertake family care work (78.5%) due to moral, legal, or cultural reasons. Only 21.5% reported having the freedom to choose whether or not to perform this task.

It must be added that women not only make up the majority of the population group providing family caregiving but also, when analyzing the profile of professional caregivers that provide support to them, the results show that most of them are women too (93.8%).

The field of family caregiving is experiencing labor market exclusion and economic precarity.

Another characteristic that defines caregivers is the lack of visibilization of their work as productive labor, as well as the low-income levels. High unemployment or inactivity rates reported among them stem from the fact that most of them are not registered in the Social Security system as caregivers (95%), mainly due to the lack of knowledge about the pertinent procedures.

5. CONCLUSIONS

Moreover, family care work affects the working life of 70.6% of caregivers, of whom 27.6% stated to have left their jobs, 14.4% have reduced their working hours, and 18.1% reported having difficulties re-entering the workforce.

As a result, the income of approximately 7 out of 10 family caregivers is equal to or less than 600 euros, with 51.6% receiving 400 euros or less, and 19.5% having no income whatsoever. Given these circumstances, many of them eventually depend financially on social benefits or the financial support of family members.

Women predominantly undertake family caregiving, often working alone and dedicating many hours each day for extended periods.

7 out of 10 women have been providing family care for a minimum of 3 years, with 25.7% for 3 to 5 years, 20.9% for 6 to 10 years, and 25.5% for more than 10 years. During this period, 1 out of 2 women reported being the main caregiver, meaning they were solely responsible for assisting dependent family members.

The situation where care work is exclusively undertaken by one caregiver is often observed among women, rather than men, since men generally tend to join collaborative dependency care networks where they share the task with other women.

As a result, most family caregivers devote a significant part of their day to this task. In fact, 47% of caregivers reported dedicating more than a full workday (9 hours or more) to caregiving, with 39.1% spending more than 12 hours daily.

5. CONCLUSIONS

Nonetheless, this labor is not only exhausting for family caregivers. When analyzing the profile of professional caregivers that assist “informal” caregivers, it is observed that 4 out of 10 work more than 40 hours a week or serve as live-in caregivers.

Among dependent individuals, many of whom do not benefit from the Dependency Act, it is important to highlight those with neurodegenerative conditions such as Alzheimer’s disease.

The majority of family caregivers provide care for a single dependent person. However, more than 15% are responsible for the care of 2 or more dependent individuals. Among them, the degree of dependency reported by caregivers was moderate (41%) and severe (38.6%).

These results significantly impact the household structure in Canarias, as 1 out of 2 caregivers lives with the dependent individual they care for. In such cases, the caregiver either had to relocate to the domicile of the person they cared for (57.9%) or vice versa (39.4%).

Parents are the primary recipients of family care (60.2%), followed by spouses and partners (13.1%) and children (10.7%). Neurodegenerative conditions are the leading cause of situations of dependency (60.3%). Many of these illnesses are associated with aging, such as Alzheimer’s disease and other dementias (36.3%).

5. CONCLUSIONS

Additionally, most dependent individuals assisted by family caregivers (75.5%) do not receive any kind of benefit or service related to the Dependency Act. Specifically, 32.4% have not applied for it, 29% have applied but are awaiting a resolution, and 14.1% are eligible but have not yet received it.

Nowadays, 19.2% of individuals in a situation of dependency receive the Economic Benefit Linked to Service (Prestación Económica Vinculada al Servicio, or PEVS), and only 1 out of 4 family caregivers is eligible for the Economic Benefit for Family Care (Prestación Económica para Cuidados en el Entorno Familiar, or PECEF) (3.9%).

The lack of knowledge concerning these resources, the steps to follow during the application process, and the perception that the procedure may not be worthwhile are some of the main reasons why people refrain from applying for these financial benefits.

Regarding the types of care provided, typically by family caregivers themselves (90.6%), it is worth noting that the most common types are instrumental care (preparing meals, housekeeping, shopping, etc.), followed by basic care (assistance with toileting, mobility, etc.) and, lastly, specialized care (administration of medical treatments, postural changes, etc.).

When performing caregiving tasks, women caregivers encounter several primary challenges daily. These challenges include, for instance, finding a balance between care work and maintaining the quality of personal, social, and work life (87.9%), dealing with behavior problems arising from specific illnesses (82.4%), the lack of knowledge about the various conditions of dependent individuals (81%) and receiving appropriate medical assistance (80.5%).

5. CONCLUSIONS

The resources provided to caregivers are insufficient for them to properly care for dependent individuals, and they face numerous obstacles when trying to access these resources.

1 out of 2 caregivers lacks any form of support resources, whether public or private. However, 52.2% of caregivers reported receiving some type of public support, while 45.7% have independently hired external assistance.

In terms of public resources, the most provided services are the Domestic Assistance Service (Servicio de Ayuda a Domicilio, or SAD) (28.7%) and the Service of Promotion of Personal Autonomy (Servicio de Promoción de la Autonomía Personal, or SPAP) (17.1%). On the other hand, in the realm of private services, hiring domestic workers (18.5%) and professional caregivers (12.1%) are the most common options.

On the topic of the current challenges concerning public administration and resources, the most relevant ones are waiting periods to access services and resources (87.6%), the lack of knowledge about available resources (84.6%), the number of hours of assistance granted (83.9%) and the bureaucratic process of applying for these resources (82.3%).

When it comes to the lack of information, family caregivers point out that units of the Public Health Service of the Canary Islands, especially the Primary Health Care unit (64.1%), as well as women caregivers' associations (23.8%) and teams of social assistance promoted by local governments of Canarias (16.8%), are the primary institutions that provide useful and effective counseling to them.

5. CONCLUSIONS

Nevertheless, 83% of family caregivers declared the need for support services to help them cope with their daily responsibilities as caregivers for family members in situations of dependency. These are the most mentioned needs: specific training to improve the quality of the care provided (dealing with illnesses, basic care, etc.) (36.2%), services that ease the burden of family caregivers (34.1%), emotional support (32.1%), and assistance with the application for sociosanitary resources (27.8%).

The resources exclusively intended for caregivers have little visibility among the caregiving community.

When women caregivers were asked if they were aware of the resources and services intended for them, 3 out of 4 reported not knowing any of them. However, among those who stated they were aware, high levels of participation and engagement were observed (more than 50%). This percentage includes associations such as El tren de la Felicidad of ACUFADE (10.7%) and the group of women caregivers of the Community Liaison Nursing (Enfermería Comunitaria de Enlace, or ECE by its Spanish acronym), a nursing system based on case management (2.4%).

The commitment required by family caregiving eventually affects the quality of life of caregivers, both physically and mentally.

9 out of 10 family caregivers claim that care work has been detrimental to their quality of life, both emotionally and physically. This effect is most pronounced among main caregivers (those who perform the task alone), with 60.5% experiencing a significant deterioration in their quality of life.

5. CONCLUSIONS

The main physical consequences are tiredness or fatigue (59.2%), followed by back and joint pain (39.4%) and general discomfort (34.2%). Emotionally, the main effects are stress (51.5%), sadness (45.5%), and anxiety (45%). Moreover, 2 out of 10 caregivers reported suffering from depression (21.6%).

Care work significantly impacts the life of caregivers, especially those aspects related to leisure and personal time, such as having time for themselves (94.2%) or engaging in leisure activities (93.3%).

Although 74.4% of women caregivers stated that self-care is important or crucial to them, 1 out of 3 caregivers spends less than 1 hour per day on self-care activities. Main caregivers are, by far, the ones who spend the least time caring for themselves, with only 1 hour or less per day.

Family caregiving has been ignored during the COVID-19 pandemic.

When asked about the impact of the coronavirus pandemic, 98.5% of family caregivers reported that their circumstances have not improved since the beginning of the sanitary crisis. Among the difficulties resulting from this situation, the most frequently mentioned ones are the lack of resources to ease the burden of caregiving (89.7%), the lack of resources and support to perform their task at home (81.3%), and delays in receiving assistance (78.5%).

5. CONCLUSIONS

Legislating and creating strategies to give visibility to care work and implement support resources intended for women family caregivers are the main claims of the caregiving community.

The main demand of this community is to highlight the need to give visibility to family care work while acknowledging the significant time and effort caregivers devote to dependent individuals. This need is constantly emphasized by caregivers: “There are not enough resources exclusively aimed at caregivers” (81.4%), “I don’t feel protected by the government (laws, rights, etc.)” (78.5%), “The value of the time and effort we put into caregiving is not acknowledged” (77.8%).

At the same time, suggestions proposed to tackle this situation are supported by almost 100% of the caregiving community:

- Developing and implementing legislation addressed to caregivers through a National Caregiving Plan (98%).
- Analyzing the situation and needs of caregivers and creating a Plan of Individualized Assistance exclusive to them (98.5%).
- Establishing a public fund exclusive to assist caregivers through emotional support, physical therapy, mutual support groups, or services intended to ease the burden of caregiving (98.2%).
- Creating a one-stop window (Ventanilla Única) where it will be possible to access information and manage all resources for caregivers quickly and efficiently (97.7%).
- Creating an identity card for caregivers that provides access to various services and benefits (94.7%).

5. CONCLUSIONS

Other actions suggested by the community of family caregivers are the following:

- Assessing the need to ease the burden of family caregivers and receive available resources from the moment they are recognized as caregivers while expecting, at the same time, that dependent individuals receive services intended for them.
- Benefiting from a legal support service exclusive to caregivers.
- Greater support from institutions regarding projects and caregiving resources that already exist, such as El tren de la Felicidad.
- Developing more accompanying protocols and care assistance protocols for emergencies and hospitalizations.
- Implementing a basic government benefit according to the level of dependency of the dependent individual. This resource will consist of a minimum income that will cover the actual costs of caregiving, which will finally lead to a dignified life for caregivers and dependent individuals.
- Erasing incompatibilities between financial benefits and services contained in the Dependency Act.
- Erasing incompatibilities between contributions to the Social Security system for caring for a dependent individual, contributions made by workers, or any kind of incapacity benefit.
- Achieving fair and well-defined conditions for the employment of professional caregivers.
- Professionalizing and legalizing family caregiving.

ACKNOWLEDGMENTS

“Gratitude must stay in our memories forever.”



ACKNOWLEDGMENTS

This Study on Family Caregivers in the Canary Islands has been made possible thanks to the ethical, professional, and moral qualities of many people who are committed to the world of caregiving and aware of the numerous challenges that caregivers face daily. We are profoundly grateful to the caregivers of the Executive Board, the Work Team of this research, the team of Case Managers and Social Workers, and the volunteering program and professionals of ACUFADE. We also want to acknowledge the network of professionals from Canarian organizations that have altruistically supported this project, as well as the Community Liaison Nursing and, ultimately, all professional women working in the healthcare system.

And, naturally, we express our heartfelt gratitude to all the women who undertake the silent labor of caregiving, enriching the well-being of those who need it the most in our region.

“We dream of a strong and recognized community of expert women caregivers where we can finally feel proud of a Society that values our knowledge and talents.”

- CAREGIVER FROM THE CANARY ISLANDS

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A STUDY ON
FAMILY
CAREGIVERS IN
THE CANARY
ISLANDS

THE RIGHT TO CARE AND BE CARED FOR

