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A Model for Dynamics in Caregivers' Personal Support Networks During the Pandemic

Rosario Fernández-Peña[1,2] | José Luis Molina[3] | Carmen Ortego-Maté[1,2] | Oliver Valero[4] |
Eider M. Arenaza-Urquijo[5,6] | Carmen Sarabia-Cobo[1,2]

[1]Nursing Department, Universidad de Cantabria, Santander, Spain | [2]Nursing Research Group (IDIVAL), Santander, Spain | [3]Department of Social and Cultural Anthropology, GRAFO, Universitat Autònoma de Barcelona, Barcelona, Spain | [4]Servei d'Estadística Aplicada, Universitat Autònoma de Barcelona, Barcelona, Spain | [5]Barcelona Institute for Global Health (ISGlobal), Barcelona, Spain | [6]Universitat Pompeu Fabra (UPF), Barcelona, Spain

Correspondence: Carmen Ortego-Maté (carmen.ortego@unican.es)

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ABSTRACT

COVID-19 public health measures significantly disrupted personal support relationships among community-dwelling family dementia caregivers. In this research, a personal network analysis was carried out to understand the dynamics in the personal support relationships of caregivers caring for persons living with dementia (PLwD) during the pandemic. The analysis focuses on variables comprising the caregivers' personal network, attributes of their alters, and the functional content in social support, as well as changes therein, before and during the pandemic. A total of 78 caregivers took part in the study, leading to an extensive analysis of 658 caregivers' personal relationships. Bivariate and multivariate regression analyses were performed to identify the characteristics of personal relationships associated with changes in the support received. The variables influencing changes were the type of tie with the caregiver and the type of support provided. The type of tie that presented the greatest positive change in support was that of caregivers' partners. In contrast, that of caregivers and health and social professionals presented the most significant negative change. Finally, the most positive change was observed in relationships that provided both emotional and informational support, whereas the least positive change occurred in relationships that offered instrumental support.

1 | Introduction

1.1 | Social Support Among Community-Dwelling Family Caregivers

In Spain, a state of alarm was declared over the COVID-19 health crisis on March 14, 2020 (BOE 2020); it ended on July 4, 2023 (BOE 2023). The preventive measures adopted to control the pandemic were at their maximum level during the lockdown, followed by other periods with less severe restrictions, which continued to affect geographic mobility, personal relationships, and social activities.

Research conducted in Spain has found that the prevalence of dementia is approximately 0.05% among individuals aged 40–65, 1.07% among those aged 65–69, 3.4% among those aged 70–74, 6.9% among those aged 75–79, 12.1% among those aged 80–84, 20.1% among those aged 85–89, and 39.2% among individuals over 90 years of age. Based on population data from the Spanish National Institute of Statistics (INE) and the above prevalence rates, over 700,000 individuals aged over 40 are currently affected by dementia in Spain. This number is projected to more than double by 2050, taking it to around 2 million people (Ministerio de Sanidad, Consumo y Bienestar Social 2019).

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Different studies have shown the consequences of the pandemic both on persons living with dementia (PLwD) and community-dwelling family caregivers. With regard to the former, the available evidence highlights the overall decline and loss of autonomy affecting different domains such as cognitive function, movement, and communication (Carcavilla et al. 2021; Rainero et al. 2021; Tsapanou et al. 2021), as well as difficulties in complying with the new measures introduced to contain the pandemic (Baumbusch et al. 2022; Chirico et al. 2022; Cipolletta et al. 2023; Mahapatra et al. 2023). As for the effects of the pandemic on caregivers, these include a negative impact on mental well-being, loneliness, stress, anxiety, depression, and difficulties in emotional management (Altieri and Santangelo 2021; Beach et al. 2021; Chirico et al. 2022; Hughes et al. 2021; Nikolaidou et al. 2022; Tsapanou et al. 2021; Wei et al. 2022; Zucca et al. 2021) as well as the exacerbation of distress due to difficulties in managing PLwD as a consequence of changes in behavior and cognition (Paplikar et al. 2022). Studies carried out in the Spanish context have shown the impact of the pandemic on the family relationships of caregivers of PLwD, including high levels of distress and a lack of social support as predictors of overload (García Santelesforo et al. 2022; Losada et al. 2022; Rodríguez-Mora et al. 2023).

Research has found that this group of caregivers considers social support to be one of the components of quality of life (Maltby et al. 2020) and both a protective and buffering factor against caregiver stress (Han et al. 2014; McAuliffe et al. 2021; Ruisoto et al. 2020). It has also been found to correlate positively with resilience (Jones et al. 2019; Wilks and Croom 2008) and has been associated with a positive perception of caregiving and motivation to perform the caregiver role (Grover et al. 2017; Nemcikova et al. 2023; Wang et al. 2022).

The impact of supportive social relationships on health has been well-established in the literature. Social support is used to refer to the social resources that persons perceive to be available or that are actively provided to them by nonprofessionals in the context of both formal support groups and informal helping relationships (Cohen et al. 2000). The perspective of the functional measurement approach assumes that there are different types of supportive functions provided through social relationships, and these functions refer to the positive, potentially health-promoting, or stress-buffering dimensions of relationships (House et al. 1988). Interestingly, these supporting relationships may interact differently with various problems or stressors (Wills and Shinar 2000), as well as the PLwD caregiver burden (Han et al. 2014).

Typically, social support has been classified into the following types: emotional support (behavior that fosters the feeling of comfort and leads a person to believe that he or she is admired, respected, and loved and that others are available to provide care and safety); informational support (knowledge, advice or information in the service of particular needs that helps an individual understand his or her world and adapt to changes that occur in it); and instrumental support (material or tangible support in terms of goods, aid, assistance or services that help solve practical problems) (Berkman et al. 2000; Jacobson 1986).

Researchers have used many general and interchangeable terms, including "social networks," "social ties," "social integration," and other constructs such as social support (Berkman et al. 2000). House et al. (1988) suggest an approach consisting of three different but interrelated dimensions: "social integration," "social network," "and relational content." Social integration or isolation refers to the number of social ties or relationships; social network structure refers to the pattern of supportive relationships, and relational content refers to the functional nature or quality of social relationships in which social support is embedded. In the same vein, Morgan (1990) suggests that personal relationships, social networks, and social support are three dimensions of the same phenomenon, suggesting the adoption of an integrative approach.

In addition, an important concept related to social support is social capital, which is seen as a valuable resource for action within the social structure, as framed in the paradigm of rational action (Coleman 1988). The development of social capital theory has introduced the distinctions of *bonding*, *bridging*, and, more recently, *linking* social capital. In this paper, we are especially interested in bonding social capital, which involves strong ties within a network that reinforces social identities and functions, serving as a source of mutual support among members. Also, bridging social capital is characterized by weaker ties that connect individuals from different networks, providing access to information and resources, whereas linking social capital is a form of bridging social capital that applies to hierarchical and vertical interactions in formal and institutionalized societal relations. These three forms of social capital may exist to varying extents within networks of individuals and can influence health through the positive effects of social support (bonding), access to diverse social clusters (bridging), and the engagement of political institutions (linking). A balanced presence of these forms of social capital is believed to be essential for the creation of healthy societies (Poortinga 2006; Szreter and Woolcock 2004).

The temporary closure of social care and social support services such as day centers, peer support groups, and social activities in the community during the pandemic led to a loss of formal resources for care and opportunities for temporary relief from care (Greenberg et al. 2020; Vislapuu et al. 2021). With regard to informal support resources generally provided by relatives, friends, or neighbors, among other individuals, these caregivers reduced their contacts and, therefore, their personal support network, both obligatorily due to public health measures and voluntarily to prevent virus transmission and reduce the risk of infection (Bergmann and Wagner 2021; Bristol et al. 2021; Shrestha et al. 2023; Tsapanou et al. 2021; Wei et al. 2022).

However, although changes in formal support resources at the community level (day centers, associations, etc.) can be assessed for specific areas or regions, changes in informal support resources must consider the different relational contexts at the individual level, highlighting the importance of personal relationships.

There is a vast literature focused on the study of personal relationships—that is, the relationships that the individual maintains with family, friends, acquaintances, and neighbors—showing the personal network dynamics throughout the life course. It is well known that changes occur not only in the size of the network but also in the individual members that comprise it and associated social support resources (Bidart and Lavenu 2005; Hollstein 2023; Volker 2020; Wrzus et al. 2013). Various studies have revealed, among other aspects, different types of support networks, characteristics of contacts, and functional content in social support in long-term conditions management (Morris et al. 2016; Vassilev et al. 2016), people with chronic pain (Fernández-Peña et al. 2020) and caregivers for people with dementia (Friedman and Kennedy 2021), demonstrating differences in personal and relational contexts, as well as in the provision/obtaining of social support.

The WHO's *Global Action Plan on the Public Health Response to Dementia 2017–2025* includes support for caregivers of PLwD among its areas of action (World Health Organization 2017). Given the new scenario during the pandemic, with additional responsibilities and changes in care routines (Irani et al. 2021; Vislapuu et al. 2021), it is essential to determine the personal support resources available to this group during the lockdown and the time in which restrictions on the mobility of people were in force, as well as any changes to these resources resulting from the pandemic.

Although different studies have focused on studying changes in caregivers' social networks and social support during the COVID-19 pandemic (Steijvers et al. 2022; Vlachantoni et al. 2022; Völker 2023), to the best of our knowledge, and despite the extensive literature on the subject, there is a gap in research on changes in personal supportive relationships affecting this group.

Our aim was to understand the dynamics in the personal support relationships of PLwD caregivers during the pandemic based on variables comprising the caregivers' personal network, attributes of their alters, and functional content in social support.

2 | Methods

2.1 | Study Design

This cross-sectional study adopted the personal network analysis (PNA) approach.

PNA is one of the approaches included within social network analysis (SNA), a research methodology that has its origins in the social and behavioral sciences and highlights the importance of relationships defined as ties between interacting units. The existing literature on social networks and health revolves around the main idea that people are immersed in a network of relationships that influence their health behaviors and resources for seeking support, meaning our health is also connected to our relationships (Smith and Christakis 2008). Social support constitutes one of the areas in which this approach is applied, providing a framework for explaining its components and allowing researchers to detect how the network variables of individual attributes and structural properties explain ties of relational support (Faber and Wasserman 2002; Smith and Christakis 2008). Thus, PNA focuses on systematically collecting the relationships surrounding an individual and analyzing the *composition* and *structure* of those relationships, the central actors being the individual participating in the study—referred to as the *ego*—and the people with whom the ego is connected—referred to as the *alters*, in all social environments in which the ego is embedded (e.g., family, work, and neighbors). Network *composition* refers to the characteristics or attributes of the network members (*alters*), both with regard to their personal data (age, sex, type of link with ego, among others) and those related to the aims of the study, in our case, functional content in social support. In addition to differences in network composition, personal networks differ in the way in which alters relate to each other, giving rise to the *network structure* (Hâncean et al. 2016; McCarty et al. 2019) through variables that reflect the cohesion or fragmentation of the network, such as density, centrality, or the number of components or isolates (Hawe et al. 2004).

2.2 | Recruitment and Participants

The study was conducted in the Autonomous Region of Cantabria (Spain), which had 585,402 inhabitants in 2022. The aging rate in Cantabria in 2022 was 23.1%, and the dependency index was 54.9%, both higher than in Spain as a whole (Cantabrian Institut of Statistics 2022). Convenience sampling was carried out to select community-dwelling family caregivers in primary care centers, day centers, and one mental health unit located in the community. Subject recruitment was carried out with the help of professionals at the different centers. The inclusion criteria were as follows: (a) being a family caregiver of a PLwD; (b) having worked as a caregiver during the COVID-19 pandemic; (c) not suffering from pre-existing psychological disorders; and (d) being willing to take part in the study.

2.3 | Data Collection

Data collection was carried out by telephone from February to October 2022. Personal support network data were collected using the EgoNet software (https://sourceforge.net/projects/egonet/), which provides network measures for structure and composition. In addition, Ucinet v.6.759 was used to compute the network structure of the matrix alter–alter for each ego. The personal network data collection survey was designed to identify the personal support networks available to dementia caregivers.

The survey included the following four modules:

a. Data from the caregiver (*ego*), including socio-demographic variables, issues related to caregiving, the cared for person, and the effects of the pandemic.

b. *Multiple name generator* questions for data collection regarding actors relevant to the personal support network in this context, including significant people (core personal networks) and the wider network, considering socialization and support resources

(Bidart and Charbonneau 2011; Burt 1984; Marin and Hampton 2007).

The name generators were as follows: Name Generator 1—"From time to time, most people discuss important matters with other people. Looking back and before the pandemic, who are those people with whom you discussed matters important to you?" Name Generator 2—"From time to time, people socialize with other people. For example, they visit each other, go on a trip together, or go out to dinner. Do not take lockdown measures due to the pandemic into account when thinking about the following question: Before the pandemic, who were the people you used to do these things with?" Name Generator 3—"In recent times (before and during the pandemic), who have you received help or social support from in your work as a carer?"

c. *Name interpreters*, used to generate attributional data for the actors (*alters*). In our study, we collected sociodemographic data for alters (age, gender, type of tie with ego) and functional content in relation to social support (type and variation).

The social support received to care for each of the alters prior to the pandemic was studied by means of a dichotomous variable (yes/no). The type of support received was collected for affirmative answers, together with any change during the pandemic, via the following categories: unchanged support, increased support, decreased support, and no longer providing support. Additionally, for each of the relationships, a textual variable was used to collect the reason given for the response regarding the change from the caregiver's perspective.

d. Name interrelating to examine relational ties between the actors (alter-alter tie) to obtain structured data.

The average duration of data collection in this phase was 45 min (ranging from 28 to 69 min).

The project was approved by the Ethics Committee for Research with Medicines (CEIm) of Cantabria (Spain) with the internal code INNVAL 20/12. Authorization was obtained from the centers included in the study; the participants were informed of the aim and procedure of the study, and their oral informed consent was obtained.

2.4 | Data Analysis

The text variables regarding the reasons for the change in support were grouped into different categories according to their meanings.

Descriptive statistics for quantitative variables are expressed as mean ± SD and range. Categorical variables are expressed as absolute and relative frequencies. Bivariate analyses were performed to compare changes in social support with the alters' characteristics. ANOVA or a Kruskal–Wallis test for quantitative variables and a chi-squared test for categorical variables were used. For each of the types of change in social support, multivariate logistic regression models were applied. Variables with a significance level of < 0.10 in the bivariate analysis were included in the multivariate analysis as fixed effects. Ego was included as a random effect. Final multivariate models were derived using the stepwise backward elimination process. Odds ratios (ORs) were calculated with 95% CI. Additionally, the change in social support was summarized in a quantitative variable in which negative and positive values were equivalent to the change in support on a gradient from loss to improvement of support: relationships that stopped providing support $= -2$; relationships in which support decreased $= -1$; relationships with no change in support $= 0$; relationships in which support increased $= 1$. This variable was analyzed in a multivariate regression model that summarizes the previous four models in one single model. Adjusted means with standard error were calculated. This variable was also used to perform bivariate analysis with ego characteristics. The *t* test or ANOVA was used for categorical variables. The analysis was performed using SAS v9.4 software (SAS Institute Inc., Cary, NC, USA). The significance level was set at $p < 0.05$.

3 | Results

3.1 | Descriptive Analysis

A total of 78 caregivers participated in the study, the majority being women (83.3%), married (69.2%) and with an average age of 61.9 years. The average time as a caregiver was 6.36 years, with an average dedication to daily care of 13.5 h. The majority (65.4%) of the caregivers lived with PLwD, and in almost half of the cases, the family home consisted of one or two people. Regarding resources for care, 19.2% of the participants did not have formal support resources, whereas day centers and paid caregivers were the most common formal support resources. Concerning the PLwD, they had a mean age of 85.23 years and were mostly women (80.8%) and parents (69.2%) of the caregivers (Table 1).

With regard to the impact of the pandemic, 57.7% ($n = 45$) considered that it affected the PLwD in the cognitive or behavioral area, 78.2% ($n = 61$) stated that it had affected them with stress or anxiety in their role as a caregiver, 78.2% ($n = 61$) that lockdown and social distancing measures had affected the care and management of their family member, and finally, 41% ($n = 32$) considered the support received to have been insufficient.

The personal support networks of the 78 caregivers consisted of a total of 658 relationships, mostly women (62.6%), with a mean of 8.4 alters (SD 3.3; range: 2–20). The most predominant type of tie with the caregiver was friend (38.1%), followed by sibling (15.2%). With regard to the functional content of social support, 13.7% of personal relationships did not provide support prior to the pandemic. The most common type of support was emotional, whether alone (41.8%) or combined with instrumental support (13.8%) (Table 2).

3.2 | Bivariate Analysis at Alter Level

In order to analyze the changes in social support received by caregivers before and during the pandemic in the 658 relationships studied (alters), 77 relationships were excluded, corresponding

TABLE 1 | Characteristics of caregivers and PLwD.

Variables	*n* (%)
Ego characteristics	
Age[a] (years)	61.9 (9.7, 38–89)
Gender	
Woman	65 (83.3)
Civil status	
Single	17 (21.8)
Married	54 (69.2)
Separated or divorced	2 (2.6)
Widowed or widowered	5 (6.4)
Members of the household	
1–2	37 (47.4)
3	23 (29.5)
4–6	18 (23.1)
Living with the PLwD	
Yes	51 (65.4)
Time as a caregiver[a] (years)	6.36 (2.86, 1–15)
Time dedicated to daily care[a] (h)	13.54 (5.96, 3–24)
Formales care support resources	
No	15 (19.2)
Day center	28 (35.91)
Paid caregiver	8 (10.26)
Day center and paid caregiver	20 (25.64)
Day center and/or caregiver for the support service for dependent people	7 (9)
Caregiver's personal network structure variables[a]	
Size	8.44 (3.33, 2–20)
Density	0.56 (0.26, 0–1)
nDegree	0.56 (0.3, 0–1)
nBetweeness	0.04 (0.1, 0–0.75)
nClosseness	0.68 (0.21, 0–1)
Centralization	0.3 (0.21, 0–0.8)
Cliques	2.59 (1.94, 0–13)
Components	1.58 (0.83, 1–4)
PLwD characteristics	
Age[a] (years)	85.23 (7.62, 64–98)
Gender	
Woman	63 (80.8)
Type of tie with ego	
Spouse	15 (19.3)

(Continues)

TABLE 1 | (Continued)

Variables	n (%)
Parents	54 (69.2)
Other relatives	9 (11.5)

[a]Mean (SD, range).

to non-support-providing relationships before the pandemic and ones that did not present any change during the pandemic.

The distribution of changes in support in the 658 relationships studied was as follows: relationships with no change in support $n=328$ (56.5%); relationships in which support increased $n=122$ (21%); relationships in which support decreased $n=91$ (15.7%); and relationships that stopped providing support $n=40$ (6.9%). When the relationships were providers of a single type of support, the most predominant was the emotional type, which was present in almost half of the relationships (48.1%) and, to a lesser extent, the instrumental and informational types (8.5% and 1.4%, respectively). When relationships presented multiple types of support, the combination of emotional and instrumental support was the most common (16.1%), followed by all three types of support (14%). Analysis of the different types of support, whether they appeared alone or in combination, was mostly dominated by the emotional type, which was present in 87.4% of the relationships, followed by the instrumental and informational types, which were present in 38.4% and 26.7% of the relationships, respectively. In 12 of the non-support-providing relationships prior to the pandemic, the alters offered support during the pandemic (Table 3).

3.3 | Modeling Changes in Social Support

In order to model the dynamic with regard to changes in support, 77 relationships were excluded that were non-support-providing before the pandemic and continued as such during the pandemic, as well as 25 relationships that, due to their characteristics, had a frequency of less than 5% of the relationships (informational support $n=8$, instrumental and informational support $n=5$ and non-support-providing before the pandemic that changed during the pandemic $n=12$). Of the total number of relationships included in the model, more than half showed no change in support during the pandemic, followed by those in which support had increased, decreased, and, to a lesser extent, relationships that had stopped providing support. Table 4 summarizes the reasons for the changes in support in each of the categories studied.

In the multivariate logistic regression model, the variables associated with the four categories of changes in social support at the alter level were the type of tie with the caregiver and the type of support provided (Table 5).

3.3.1 | Relationships With no Change in Social Support

Of the total relationships studied, 325 (58.4%) remained unchanged. Partners (74.7%) and other relatives (59.4%) were the ones who continued to offer the highest proportion of unchanged support, whereas children (30.7%) and caregivers/health personnel (32.4%) presented the lowest percentages. Relationships in which the support provided did not change were up to six times more common when the type of tie was the partner than when it was the children, and this was true for approximately three times more than in the case of friends, neighbors, coworkers, and other relatives. No statistically significant differences were observed with siblings, caregivers, and professionals.

When the type of support was emotional, up to seven times more relationships did not change than when the support was instrumental, and this figure was 3.4 times more than when emotional support was combined with informational support. No statistically significant differences were observed when emotional support was combined with instrumental support or in the relationships providing the three types of support (Table 5.1).

3.3.2 | Relationships With Increased Social Support

Social support during the pandemic increased in 106 of the relationships studied (19.1%).

The types of ties with the caregiver in which support relationships increased in the greatest proportion were with children (26.9%) and siblings (20.8%), whereas those in which it increased least were in the case of friends, neighbors, and coworkers (9.0%) and other relatives (10.0%). The type of support most present in these relationships was emotional combined with informational support (26.3%), and the least was instrumental support (4.93%).

The increase in the support provided by caregivers' children and siblings was 3.7 and 2.6 times greater than that provided by friends, neighbors, and coworkers. No statistically significant differences were observed with other relatives, caregivers, professionals, or partners. As for the type of support, emotional combined with informational support and all three types of support were 6.8 and 6 times higher, respectively, than in relationships providing instrumental support. No statistically significant differences were observed in the relationships in which only instrumental support was present (Table 5.2).

3.3.3 | Relationships in Which Support Decreased During the Pandemic

Social support decreased during the pandemic in 90 of the relationships studied (16.2%). As for types of ties with the caregiver in which support relationships decreased, the higher proportions were found with children (22.4%) and other relatives (20.2%), whereas the types of relationships in which support decreased most were those that provided instrumental support (24.9%).

TABLE 2 | Personal social support caregivers (658 alters).

Variables	*n* (%)
Alter's age[a]	55.11 (14.87, 7–96)
Alter's gender	
Woman	412 (62.6)
Tie to ego	
Friends	251 (38.1)
Siblings	100 (15.2)
Parents	6 (1)
Children	95 (14.4)
Partner	41 (6.2)
Caregivers/professional health or social	44 (6.7)
Neighbors and coworkers	23 (3.5)
Other relatives	98 (14.9)
Functional content in social support	
Relationships providing support prior to the pandemic	568 (86.3)
Relationships not providing support prior to the pandemic	90 (13.7)
Type of support	
Emotional	275 (41.8)
Instrumental	48 (7.3)
Informational	8 (1.2)
Emotional and instrumental	91 (13.8)
Emotional and informational	63 (9.6)
Instrumental and informational	5 (0.8)
Emotional, instrumental, and informational	79 (12)

[a] Mean (SD, range).

Support provided by the caregivers' children and other relatives decreased 17.8 and 15.5 times more, respectively, than that provided by partners. No statistically significant differences were observed for caregivers and professionals. As for the type of support, relationships in which emotional and instrumental support was provided decreased 12.2 times more than those that provided solely emotional support. Also, the older the ego, the more relationships in which social support decreases. No statistically significant differences were observed in relation to solely emotional support relationships (Table 5.3).

3.3.4 | Relationships That Stopped Providing Support During the Pandemic

Social support stopped being provided during the pandemic in 35 of the relationships studied (6.3%). Caregivers and professionals were the ones who most commonly stopped providing support to caregivers (28.4%), whereas the least common were partners and other relatives (0.48%). The type of support that stopped being provided most during the pandemic was instrumental (32.1%), with emotional support the least (1.2%).

Caregivers and health and social professionals stopped offering support 81.8 times more than partners and other family members. Instrumental support was no longer offered to caregivers 40.1 times more than emotional support and 36.3 times more than emotional and informational support (Table 5.4).

3.4 | Dynamics in Social Support: A Summary Model

With the aim of analyzing changes in support in a single model, we created a new quantitative variable in which the negative and positive values were equivalent to the change in support on a gradient from loss of the support received to improvement in it: relationships that stopped providing support ($n = 40$) = −2; relationships in which support decreased ($n = 91$) = −1; relationships with no change in support ($n = 328$) = 0; relationships in which support increased ($n = 122$) = 1. Variables related to the changes in social support received before and during the pandemic were type of tie with caregiver (p value < 0.0001) and type of support (p value < 0.0001) (Table 6).

The caregivers' partners were the type of tie that presented a greater change in support in a positive sense, whereas caregivers and professionals presented the greatest change in a negative sense. Caregivers' children and siblings were the ones that presented the fewest changes in the support provided before and during the pandemic. Regarding the change in support according to type, relationships providing emotional support combined with the informational type presented the greatest change of support in a positive sense, followed by solely emotional. On the other hand, relationships providing instrumental support were the ones that presented the greatest change in a negative sense.

3.5 | Bivariate Analysis at the Ego Level

In the bivariate analysis between the summary variable of the variation in social support received and ego characteristics, only the duration of dementia suffered by the PLwD presented statistically significant differences (p value < 0.014). No statistically significant relationships were found between the variation in social support and the personal network structure indicators. Caregivers of PLwD with fewer than 5 years of dementia presented a positive mean variation, indicating a predominance of relationships in which support remained unchanged or increased during the pandemic (mean = 0.13; SD = 0.45; range = 0.75–1), whereas caregivers of PLwD suffering dementia for between 5 and 9 years presented a negative mean variation (mean = 0.17; SD = 0.41; range = 1–1), indicating a predominance of relationships in which support decreased or stopped. Finally, in caregivers of PLwD

TABLE 3 | Changes in support relationships during the pandemic.

	Total ($N = 581$)	No change ($n = 328$)	Increase ($n = 122$)	Decrease ($n = 91$)	Stopped providing ($n = 40$)	*p*
Age[a]	54.82 (15.03)	56.80 (14.40)	53.30 (15.92)	51.91 (15.19)	49.97 (14.61)	0.002
Gender						0.005
Women	363 (62.5)	212 (64.6)	62 (50.8)	57 (62.6)	32 (80.0)	
Tie with caregiver						< 0.001
Sibling	96 (16.5)	40 (12.2)	29 (23.8)	21 (23.1)	6 (15.0)	
Child	91 (15.7)	31 (9.5)	31 (25.4)	25 (27.5)	4 (10.0)	
Partner	38 (6.5)	26 (7.9)	11 (9.0)	1 (1.1)	—	
Other family member	89 (15.3)	53 (16.2)	14 (11.5)	21 (23.1)	1 (2.5)	
Friend, neighbor, coworker	230 (39.6)	168 (51.2)	33 (27.0)	21 (23.1)	8 (20.0)	
Caregivers and professionals	37 (6.4)	10 (3.0)	4 (3.3)	2 (2.2)	21 (52.5)	
Type of support						< 0.001
Emotional	272 (48.1)	207 (63.3)	42 (38.9)	18 (19.8)	5 (12.5)	
Instrumental	48 (8.5)	15 (4.6)	3 (2.8)	9 (9.9)	21 (52.5)	
Informational	8 (1.4)	2 (0.6)	3 (2.8)	1 (1.1)	2 (5.0)	
All three types	79 (14.0)	27 (8.3)	26 (24.1)	21 (23.1)	5 (12.5)	
Emotional and instrumental	91 (16.1)	36 (11.0)	18 (16.7)	35 (38.5)	2 (5.0)	
Emotional and informational	63 (11.1)	39 (11.9)	15 (13.9)	7 (7.7)	2 (5.0)	
Instrumental and informational	5 (0.9)	1 (0.3)	1 (0.9)	—	3 (7.5)	
Missing	3 (0.6)	3 (0.6)	—	—	—	
Emotional support						< 0.001
Yes	508 (87.4)	310 (94.5)	103 (84.4)	81 (89.0)	14 (35.0)	
No	73 (12.6)	18 (5.5)	19 (5.6)	10 (11.0)	—	
Instrumental support						< 0.001
Yes	223 (38.4)	79 (24.1)	48 (39.3)	65 (71.4)	31 (77.5)	
No	358 (61.6)	249 (75.9)	74 (60.7)	26 (28.6)	9 (22.5)	
Informational support						< 0.001
Yes	155 (26.7)	69 (21.0)	45 (36.9)	29 (31.9)	12 (30.0)	
No	426 (73.3)	259 (79.0)	77 (63.1)	62 (68.1)	28 (70.0)	

(Continues)

TABLE 3 | (Continued)

	Total ($N = 581$)	No change ($n = 328$)	Increase ($n = 122$)	Decrease ($n = 91$)	Stopped providing ($n = 40$)	p
Provided support during pandemic (not provided prior to it)						< 0.001
Yes	12 (2.1)	—	12 (9.8)	—	—	
No	569 (97.9)	328 (100.0)	110 (90.2)	91 (100.0)	(100.0)	

[a] Mean (SD).

TABLE 4 | Changes in social support during the pandemic and reasons.

	N (%)	Reasons
Relationships with no change in support	325 (58.45)	– Support was maintained by telephone or video call. – Alters were cohabitants.
Relationships with increased support	106 (19.06)	– Increased calls or video calls to provide support. – Alter's concern about the ego's situation as a caregiver. – Cohabitants with more presence at home due to not working or teleworking during the pandemic.
Relationships with decreased support	90 (16.20)	– Lockdown and fear of contagion. – Alter illness during the pandemic.
Relationships that stopped providing support	35 (6.29)	– Lockdown and fear of contagion.
Total	556 (100)	

suffering more than 10 years of dementia, the summary value of the variation was more significant in the negative direction (mean = 2; SD = 0.38; range = 1.14–0.33), reflecting a more significant loss of support relationships (Table 7).

4 | Discussion

The aim of this study was to understand the dynamics in the personal support relationships of PLwD caregivers during the pandemic based on variables comprising the caregivers' personal network, attributes of their alters, and functional content in social support, looking for variables associated with the variation in social support received. Overall, it is worth noting that around 60% of the relationships did not show any change in the support provided, whereas in around 20% of the relationships, the support increased, and in 20%, the support decreased or was no longer provided. Two variables reflecting personal network composition were associated with these changes in the social support received: the type of social support and the type of tie that the alter maintains with the caregiver.

Regarding the type of social support present in the caregivers' personal networks, it is worth noting the differences found between emotional and informational support relationships on the one hand and instrumental support on the other.

Cheng et al. (2013) found that those providing emotional support were the most common personal relationships among this group of caregivers, and in our results, these types of relationships were the ones that remained unchanged to the greatest degree. This positive change was observed both in personal relationships where there was solely emotional support and when this type of support was combined with informational support, the latter being especially relevant for caregivers managing the new situation during the pandemic (Flemons et al. 2022). In this regard, it is important to note the different types of transmission channels in social support relationships since emotional and informational support transmitted by telephone or video call was not affected by the preventive measures adopted during the pandemic (Cousins et al. 2022; Rotondo et al. 2022; Vlachantoni et al. 2022), and even increased because of the caregivers' concern to provide online support. On the other hand, and in accordance with the findings of other studies, instrumental support exhibited the most negative change, decreasing or ceasing altogether (Benke et al. 2020; Carcavilla et al. 2021; Schultz et al. 2022; Vislapuu et al. 2021; Völker 2023) due to the caregivers' own volition in order to limit contact and therefore the risk of contagion. Our results show that lockdown and social distancing measures affected the care and management of PLwD provided by 78.2% of caregivers. The necessary presence or face-to-face contact of the alter as a transmission channel for providing instrumental support at least partly explains the decrease or cessation of this type of support, thus limiting the availability of support in the caregivers' personal networks. This situation has highlighted the role of cohabitants, especially during lockdown and in PLwD caregivers who had the disease for a more extended period, who were most likely the ones with more need for instrumental support due to the evolution of the illness.

TABLE 5 | Modeling.

	OR	95% CI	*p*
5.1 Relationships with no change in social support			
Type of tie with caregiver			< 0.001
Siblings vs. children	1.77	0.85–3.66	
Other relative vs. children	3.30	1.54–7.09	
Friends, neighbors, coworkers vs. children	2.94	1.50–5.78	
Caregiver/healthcare or social professional vs. children	1.08	0.37–3.14	
Partner vs. children	6.65	2.59–17.06	
Type of support prior to the pandemic			< 0.001
Emotional vs. instrumental	6.97	2.85–17.06	
Emotional and instrumental vs. instrumental	1.20	0.47–3.06	
Emotional and informational vs. instrumental	3.41	1.25–9.30	
All three types vs. instrumental	1.05	0.41–2.71	
5.2 Relationships with increased social support			
Type of tie with caregiver			0.010
Sibling vs. friends, neighbors, coworkers	2.65	1.22–5.79	
Child vs. friends, neighbors, coworkers	3.73	1.77–7.86	
Other relative vs. friends, neighbors, coworkers	1.13	0.46–2.75	
Caregiver/healthcare or social professional vs. friends, neighbors, coworkers	1.52	0.39–5.87	
Partner vs. friends, neighbors, coworkers	2.30	0.83–6.35	
Type of support prior to the pandemic			0.065
Emotional vs. instrumental	3.56	0.87–14.63	
Emotional and instrumental vs. instrumental	3.62	0.85–15.44	
Emotional and informational vs. instrumental	6.87	1.50–31.40	
All three types vs. instrumental	6.01	1.43–25.32	
5.3 Relationships with decreased social support			
Type of tie with caregiver			0.025
Sibling vs. partner	11.93	1.43–99.65	
Child vs. partner	17.76	2.13–147.87	
Other relative vs. partner	15.53	1.81–132.91	
Friends, neighbors, coworkers vs. partner	13.99	1.60–122.09	
Caregiver/healthcare or social professional vs. partner	2.10	0.16–27.67	
Type of support prior to the pandemic			< 0.001
Instrumental vs. emotional	5.68	1.79–17.96	
Emotional and instrumental vs. emotional	12.21	5.41–27.55	
Emotional and informational vs. emotional	1.83	0.68–4.93	
All three types vs. emotional	8.68	3.53–21.38	
5.4 Relationships that stopped providing social support			
Type of tie with caregiver			< 0.001
Caregiver/healthcare or social professional vs. siblings	11.84	2.62–53.62	
Caregiver/healthcare or social professional vs. children	18.16	3.76–87.74	

(Continues)

TABLE 5 | (Continued)

	OR	95% CI	*p*
Caregiver/healthcare or social professional vs. partner and other relative	81.83	8.09–826.97	
Caregiver/healthcare or social professional vs. friends, neighbors, coworkers	6.54	1.11–38.46	
Type of support prior to the pandemic			< 0.001
Instrumental vs. emotional	40.12	6.35–253.34	
Instrumental vs. emotional and instrumental	21.07	3.42–129.98	
Instrumental vs. emotional and informational	36.33	4.75–277.73	
Instrumental vs. all three types	8.98	2.04–39.59	

TABLE 6 | Summary model.

	Estimate	Standard error
Type of tie with caregiver (alter)		
Sibling	−0.1277	0.0797
Child	−0.0993	0.0796
Other relative	−0.1920	0.0844
Friends, neighbors, coworkers	−0.3077	0.0700
Caregiver/healthcare or social professional	−0.7429	0.1270
Partner	0.1557	0.1160
Type of support prior to the pandemic (alter)		
Emotional	0.0757	0.0649
Instrumental	−0.8297	0.1081
Emotional and instrumental	−0.3011	0.0802
Emotional and informational	0.1326	0.0989
All three types	−0.1724	0.0852

In addition to the informal support resources available in their personal networks, most of the participants had access to formal support resources through paid caregivers or day centers. It turned out that access to formal support was more beneficial to caregivers than enhanced informal support (Jarrott et al. 2005). Moreover, the lack of access to formal support affects the capacity of informal support to mitigate the burden perception by caregivers (Antelo and Espinosa 2022). According to our results, these formal support relationships made up of paid caregivers and health and social professionals presented the greatest change in a negative sense. With regard to this, different studies have shown a decrease or absence of paid caregivers in homes due to confinement or fear of contagion (Cohen et al. 2020; Giebel et al. 2020; King et al. 2023), as well as the loss of help from day centers due to their temporary closure during lockdown (Greenberg et al. 2020; Vislapuu et al. 2021).

This reveals the increased responsibility on caregivers when it came to providing care, and their being exposed to greater stress when managing complex care situations without external help (Canevelli et al. 2020). In this regard, 41% of participants considered that the support they received to carry out their care duties was insufficient, and 78.2% considered that the pandemic affected them in their role as caregivers in the form of anxiety or stress.

Regarding cohabitation, the review work by Chiao et al. (2015) showed that living with PLwD is a characteristic associated with the caregiving burden, so during the pandemic, these caregivers, and especially spouses of PLwD—which in our study comprised almost 80% of the participants—formed a profile of especially vulnerable caregivers when considering support received for caring (Rokstad et al. 2021). Regarding the type of support, instrumental support resources stood out in this context, with family ties being common sources of support (Nishio et al. 2017). However, these were limited due to the pandemic, especially in the case of non-cohabiting children, who were the main providers of support for spouses of PLwD.

On the one hand, in a positive sense, in contexts in which members of the family worked from home during the pandemic, the caregivers were therefore able to avail themselves of their support with regard to care. In a negative sense, it is in those caregivers with small personal networks and/or few cohabitants. In relation to size, the networks studied here had an average of around eight alters, similar to the study on this type of caregiver conducted by Friedman and Kennedy (2021). The minimum range was situated at two alters. Along the same lines, different studies have highlighted that due to prolonged dedication to care, this group experiences a reduction in their social life, with a loss of relationship opportunities and the experience of social isolation and loneliness (Brodaty and Donkin 2009; Tatangelo et al. 2018; Victor et al. 2021), which indirectly affects informal support. In addition to the availability of support in relation to network size, larger and more diverse networks have been associated with lower levels of stress, worry, and fatigue during the pandemic (Nitschke et al. 2021).

In the overall assessment of the social support received, it is necessary to consider the association between types of support and different dimensions of caregiver burden (Ankri

TABLE 7 | Bivariate analysis with Ego characteristics.

	Mean (range)	*p*
Gender		0.651
Men	−0.14 (−1.00; 0.90)	
Women	−0.08 (−1.14; 1.00)	
Age		0.986
< 60 years	−0.09 (−1.00; 0.83)	
60–69 years	−0.08 (−1.14; 1.00)	
70+ years	−0.09 (−0.64; 0.43)	
Civil status		0.062
Single	−0.24 (−0.75; 0.38)	
Married	−0.01 (−1.00; 1.00)	
Others	−0.13 (−1.14; 0.29)	
Cohabitants		0.111
1	−0.07 (−0.40; 0.17)	
2	−0.22 (−1.14; 0.43)	
3	0.07 (−0.75; 1.00)	
4+	−0.05 (−1.00; 0.83)	
Education		0.387
Primary education	−0.19 (−1.00; 1.00)	
Vocational training	0.00 (−0.75; 0.83)	
University studies	−0.09 (−1.00; 0.60)	
Baccalaureate	0.02 (−1.14; 1.00)	
Employment situation		0.898
Employee	−0.06 (−1.00; 0.83)	
Unemployed	−0.04 (−0.75; 1.00)	
Retired	−0.10 (−1.14; 1.00)	
Other situations	−0.17 (−0.75; 0.90)	
Residential location type		0.100
Rural	−0.25 (−1.14; 0.25)	
Intermediate	0.06 (−1.00; 1.00)	
Urban	−0.13 (−1.00; 0.90)	
Gender PLwD		0.865
Men	−0.07 (−0.64; 0.33)	
Women	−0.09 (−1.14; 1.00)	
Tie with PLwD		0.673
Spouse	−0.18 (−1.00; 0.43)	
Father/mother	−0.06 (−1.14; 1.00)	
Other family member	−0.07 (−0.50; 0.29)	
Cohabits with person with dementia		0.399
Yes	−0.12 (−1.14; 1.00)	
No	−0.03 (−1.00; 0.90)	
Time of dementia		0.014
< 5 years	0.13 (−0.75; 1.00)	
5–9 years	−0.17 (−1.00; 1.00)	
10+ years	−0.20 (−1.14; 0.33)	
Care time		0.121
< 5 years	0.05 (−1.14; 1.00)	
5–9 years	−0.18 (−1.00; 1.00)	
10+ years	−0.05 (−0.50; 0.33)	
Hours dedicated to care		0.844
< 10 years	−0.08 (−1.00; 0.90)	
10–19 h	−0.11 (−1.00; 1.00)	
20+ hours	−0.03 (−0.50; 0.33)	

(Continues)

TABLE 7 | (Continued)

et al. 2005). Thus, although instrumental support has been found to reduce nonpsychological burden, emotional support, and positive interactions have been associated with resilience and shown to be beneficial for psychological burden (Bressan et al. 2020; Han et al. 2014; Jones et al. 2019). In addition to assessing types of support, it is therefore necessary to take into account the coping styles (Nishio et al. 2017; Owokuhaisa et al. 2023) and resilience displayed by these caregivers (Cross et al. 2018).

In this scenario, it is necessary to consider the network variables, especially the functional content and social support in the different personal contexts of PLwD caregivers, to implement social network interventions (Dam et al. 2016), taking into account how health crises can affect the provision of the different types of support needed by PLwD caregivers.

Finally, regarding the relationship between personal network structure indicators and changes in the social support received, no statistically significant relationships were detected, most likely due to the limited number of cases included in the study. Future studies with larger samples could aim to highlight the role played by these indicators.

To our knowledge, although other studies have used our perspective from the PNA in the study of social support received by caregivers of PLwD during the pandemic (Kennedy et al. 2024), there are no others that have explored the impact of the pandemic on the provision–reception of social support in its different types.

5 | Conclusion

In a health crisis, it is necessary to consider the availability of both formal and informal resources for care. Concerning the latter, it is essential to detect the most vulnerable personal and relational contexts in terms of the quantity and quality of supportive relationships, with the aim of guaranteeing complementarity with other resources. Future research based on the network approach would allow us to gain a further in-depth understanding of the reality experienced by these caregivers in terms of their personal, informal support resources. This approach would allow us to establish their personal needs as caregivers, as well as the design and implementation of social network interventions to prevent decreased physical, mental, and social well-being in this group.

6 | Study Limitations

Several limitations should be acknowledged with regard to this study. First, the selection of participants via professionals from health and social centers, in some cases, made access to these participants difficult due to new professional activities in their centers related to the pandemic during the sampling phase. Second, those family caregivers who did not meet the appropriate conditions to participate by telephone—mainly due to their age and care situation during the pandemic—were left out of the study. Finally, the type of sampling and the limited number of caregivers included in the study did not allow us to reach conclusive results regarding changes in support relationships, as well as other sociodemographic and care variables studied at the ego level. All that being said, however, our study does provide empirical results at a relational level from the perspective of caregivers, which has allowed us to collectively understand the personal and relational support environment of this group and its behavior during the pandemic.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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