Italian Sociological Review
ISSN 2239-8589
DOI: 10.13136/isr.v15i14(S).1093 2025, 15(14S), pp. 983 – 1012

Care Relationships, Social Capital and Well-Being in the Caregiving of Persons With Disabilities: Evidence From a Qualitative Study in Italy[*]

Fabio Ferrucci[a], Giuseppe Monteduro[a]

Abstract

This study examines the forms of caregiving directed toward persons with disabilities, focusing on the role of informal support relationships and the types of social capital mobilized by family caregivers. The objectives were to (a) understand how care relationships are configured in everyday life, their meanings, and their effects on caregivers' lives; (b) identify the role and functions of the reference person -the person who helps the caregiver the most-ithin support networks; and (c) explore how bonding and bridging social capital influence caregiving practices and caregivers' well-being.

A mixed-methods design was adopted, consisting of 30 dyadic interviews with caregiver–reference person pairs, combined with Personal Network Analysis to map personal support networks. The interviews explored emotional and material challenges, meanings attributed to caregiving, access to social and health services, and representations of the future. Transcripts were analyzed through thematic coding, while Personal Network Analysis assessed network size, density, and alter attributes.

Findings indicate that caregiving often takes the form of "perpetual parents" – a totalizing, continuous, and pervasive relationship that reshapes caregivers' biographies and limits opportunities for employment, social participation, and self-determination. While participants reported prolonged stress, social isolation, and professional sacrifices, they also described emotional recognition and symbolic gratification. Care networks were predominantly characterized by familial bonding social capital, with bridging capital playing a crucial yet less developed role.

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[*] Although the work reflects the views of all authors, sections 1 and 2 were written by Giuseppe Monteduro, sections 3 and 4 were written by Fabio Ferrucci. All other sections are to be attributed to the two authors equally.

[a] University of Molise, Campobasso, Italy.

Corresponding author:
Fabio Ferrucci
E-mail: ferrucci@unimol.it

Received: 19 November 2025
Accepted: 23 December 2025
Published: 30 December 2025

The study underscores the centrality of informal networks in sustaining caregiving in Italy and highlights the need to strengthen community-based supports and public infrastructures to ensure continuity of care and enhance both caregiver well-being and autonomy for persons with disabilities.

Keywords: caregiving, disability, social capital, informal networks, mixed methods, family care.

1. Introduction

The topic of caregiving represents a crucial issue in contemporary societies (Nadash & Miller, 2025; Bruhn & Rebach, 2014; Fine, 2007). Driven by the dynamics of population ageing, it has progressively gained a central position in the welfare policy agendas of many countries (Charalambous, 2023; Rocard & Llena-Nozal, 2022). Although often identified with long-term care policies for the elderly, caregiving for young and adult persons with disabilities (PwD) presents specific and distinctive features (Kittay, 2019, 1999; Freitag, 2018; Sanderson et al., 2017; Power, 2016; Talley & Crews, 2012). Within a context of a progressive welfare crisis, the figure of the family caregiver[1] stands at the intersection of affective, practical, and social responsibilities (COFACE, 2017; Zehner Ourada, Walker 2014 Marchisio & Curto, 2011; Thorne, 2004).

Care work, understood as an ongoing relational activity, has sociological significance because it represents both a conditioning factor for the caregiver (Finch & Groves, 2022) and a potential leverage for opening or expanding the social networks of the person with a disability[2] (Li et al., 2023). The sociological literature has long emphasised the multiple dimensions that characterise care work (Thomas, 1993; Tronto 1993). Emslie et al. (2009) distinguish between the practical dimension of care work ("*caring for*") and its emotional dimension ("*caring about*"). The first refers to assistance with personal hygiene, meal preparation, paperwork, and mobility; the second concerns listening, sharing emotions, and providing psychological support to sustain the PwD's well-being.

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[1] Informal family caregiver is a person who provides: "(1) routine activities of daily living (for example, bathing, toileting and eating); (2) instrumental activities of daily living (for example, housework, transportation, and managing finances); (3) companionship and emotional support; and (4) medical and nursing tasks, such as injections and colostomy care (Li, Song 2021, p.1906). Throughout the text, caregiver will be identified with the acronym CG.

[2] Throughout the text, persons with disabilities will be identified by the acronym PwD.

However, emotional work can take on different connotations: on the one hand, it may be a source of stress, material insecurity, and social marginality; on the other hand, it can be an experience of meaning, reciprocity, and identity construction (Daly & Lewis, 2018). The analysis of caregiving relationships cannot, therefore, be reduced merely to the functional dimension of assistance, but must be interpreted as a process of meaning-making, social identity formation, and reciprocal recognition within a framework of persistent constraints (Stapley et al., 2025; Bixby, 2023; Montgomery & Kosloski, 2009; Thomas, 1993).

This article presents and discusses the main findings of a study conducted within the framework of the project *Social capital as resource of care practice in Italy: Caregiving and social support in pandemic time*. Using a mixed-method approach, the project aimed to: (a) reconstruct the trust-based and cooperative networks available to caregivers involved in supporting, among others, older adults and PwD; and (b) identify the key mechanisms shaping the role and operation of caregivers in Italy, starting from a nationwide survey on the willingness of adults to provide social support.

The research framework places the concept of social capital at the centre, as it allows for interpreting informal support networks as relational resources available to caregivers that help alleviate the burden of care (Barrett et al., 2014). Among the various theoretical perspectives on social capital[3], this study adopts an approach that views it as a quality of social relations and networks (Degenne & Forsé, 2004; Donati, 2007; Donati & Tronca, 2008). Within the theoretical framework of structural interactionism (Degenne & Forsé, 2004; Tronca, 2013; Tronca & Sità, 2019), social capital is conceived as a web of social relations that constitutes a resource for those who establish and maintain it – it is made up

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[3] Although the concept of social capital is an umbrella term, it has different meanings depending on the authors who have theorised it. A first approach was developed by James Coleman (1988, 1990), for whom social capital consists of the set of resources inherent in social relations that facilitate individual action. A second approach was developed by Pierre Bourdieu (1980, 1986), according to whom social capital is a form of capital, like economic and cultural capital, and concerns resources that are accessible thanks to the possession of a lasting network of relationships. Putnam (1993, 2000) defines social capital as the set of norms of reciprocity and networks of association that promote cooperation and the quality of democratic life. Alongside these three paradigms, there are more recent developments that broaden the concept: Lin (2001) insists on the measurability of resources obtainable through social networks. For Donati (2007, 2014), on the other hand, social capital is a relational asset that emerges from the quality of relationships based on reciprocity, trust and mutual recognition. In this perspective, social capital is an outcome of relational processes (an emergent effect) and not an individual or structural attribute.

of what circulates within networks and of the networks' very structure (Forsé, 1997; Lin, 2001; Degenne & Forsé, 2004; Forsé & Tronca, 2005; Di Nicola et al., 2011).

Accordingly, this article pursues two objectives: (a) to present the forms of involvement and relational investment required of caregivers, by analysing the care relationships and support mechanisms activated around caregivers of PwD (only under 65 years of age); and (b) to highlight both the relational and symbolic resources mobilised to sustain this commitment and the forms of social capital upon which caregivers rely. The literature distinguishes between bonding social capital, grounded in strong and intimate ties – often the primary source of care – and bridging social capital, built through weaker ties and professional or associative networks that provide access to external resources and institutional recognition (Lin, 2001). Special attention will be paid to the *person of reference*[4], who emerges as a key node within the support network.

The following sections describe the methodological aspects of the study, present the empirical results (discussed in Section 5), and conclude with reflections emerging from the analysis.

2. Methodology

The study used a mixed-methods approach to capture the complexity of care relationships from the perspectives of those directly involved in caregiving.

The sample consisted of 30 dyads, each made up of: (a) one caregiver (CG) of a person with a disability (PwD), and (b) one person of reference (PR) identified by the caregiver as a significant figure providing support in their care commitment toward the PwD[5].

In line with the theoretical framework, two instruments were employed for data collection: a dyadic interview, and a *Personal Network Analysis* (PNA) form.

Through the dyadic co-presence interview (Bramanti et al., 2023; Szulc & King, 2022; Caldwell, 2014; Morgan et al., 2013), information was gathered from both the caregiver and the person of reference regarding the functional and symbolic characteristics of their relationship, focusing on the following thematic areas: the care relationship, the caregiver's well-being, access to services, trust resources, and representations of the future.

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[4] Throughout this text, the term 'reference person' will be identified by the acronym PR.

[5] In this study, we considered only those CGs that could indicate a reference person. There are cases of CG without social support, but for the purposes of this research, such cases were excluded from the study.

The personal network analysis forms, used to map the personal support networks of all individuals interviewed, enabled the researchers to delineate the structural configuration of the relational environment in which respondents are embedded.

Respondents (egos) were asked to complete[6]: *i*) a name generator aimed at identifying the list of "alters" (contacts) to whom they had provided help at least once during the previous 12 months (including PwD); and *ii*) an additional supplementary name generator designed to capture the alters from whom they had received help[7] – without necessarily having reciprocated it – over the same period.

In addition, name interpreters were used to obtain information on the personal attributes of alters and on the characteristics of ego–alter relationships. The relational data thus collected allowed classification of alters by their attributes and the social circles to which they belonged, enabling assessment of network homophily and identification of the morphological features of each respondent's network.

Initially, the research design followed a dual recruitment criterion for participant selection: 15 caregivers of PwD were included in programs aimed at fostering autonomy and social inclusion; and 15 caregivers of PwD involved in programs such as *Dopo di Noi*[8] ("After Us") or *Independent Living Projects*[9].

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[6] Ego corresponds to the CG.

[7] The type of help received was classified as follows: financial assistance, material assistance (personal hygiene, cooking, accompaniment to medical visits), information, transfer of reputation, contacts and interpersonal knowledge, and strategies for dealing with problems.

[8] 'Dopo di Noi' is a set of measures governed by Law 112/2016, which aims to support people with severe disabilities who lack family support, ensuring their autonomy, well-being and full social inclusion even after the death or incapacity of their parents or family members. The measures include support for independent living in housing solutions, skills development programmes and internships for inclusion, and assistance in managing the assets allocated to the disabled person. The resources come from the 'Dopo di Noi' Fund and are disbursed through individualised projects defined at regional level.

[9] The 'Independent Living Project' is a measure that aims to guarantee people with disabilities the right to autonomy, self-determination and full social inclusion, allowing them to live independently and make decisions about their own lives. Italian regions and municipalities implement these projects, offering support such as personal assistance, transport and housing, in line with Regional Guidelines and regulatory provisions such as Article 14 of Law 328/2000 and Law 162/1998.

A second criterion concerned territorial differentiation: for each of the two groups, one-third of the interviews involved caregivers living in Northern Italy, one-third in Central Italy, and one-third in the South and Islands.

Most of the interviews (25 out of 30) were conducted by a researcher on the project team who was specifically trained to administer both the dyadic interviews and the PNA instruments. The remaining five interviews (5/30) were carried out by an external research agency, SWG[10], as part of a collaboration agreement with the PRIN research unit of the University of Molise.

The fieldwork phase began in March 2024 and concluded in September 2025. Despite the collaboration of several disability-related associations, access to participants proved challenging. From the outset, some potential participants could not be reached using available contact information. Others declined participation due to the time required to complete both the interview and the co-presence session with the PR, which was incompatible with their caregiving responsibilities.

To achieve the number of dyadic interviews established in the project design, the team opted for a snowball sampling method, which ultimately reshaped the sample composition – both in terms of caregivers' participation in autonomy-enhancing projects and their geographical distribution.

The initial recruitment rationale was based on the hypothesis that the networks of caregivers of PwD involved in independence-promoting programs would differ morphologically from those of caregivers of PwD not participating in such programs. Two key assumptions guided this design: 1) a higher endowment of social capital would enhance caregivers' and PwD's self-esteem, self-efficacy, and personal well-being; 2) a rich and participatory relational context would predict the caregiver's ability to co-design and co-manage independent living and *Dopo di Noi* projects involving the PwD.

Although the final sample did not fully reflect the original design, the resulting relational networks still displayed morphological characteristics that allowed a partial verification of these hypotheses.

Data collected through the instruments included: (a) socio-demographic characteristics of participants, (b) the structure of support networks, and (c) concrete caregiving practices in daily life.

Due to the requirements of the co-presence interviews and the depth of the topics discussed, each dyadic interview[11] lasted an average of approximately 33 minutes. All interviews were subsequently fully transcribed and thematically coded (Braun & Clarke, 2019), enabling the identification of recurrent analytical

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[10] https://www.swg.it/

[11] All interviews were conducted in Italian, audio recorded and with the informed consent of the interviewees regarding privacy. Quotes are reported anonymously.

themes such as *perpetual parenthood*, *pervasiveness of care*, *emotional ambivalence*, *the role of the person of reference*, and *bonding and bridging social capital.*

3. Characteristics of the dyads and their relational networks

The demographic profile of the respondents (see Table 1) shows that the CG is predominantly female (28 out of 30). Among PR, 13 out of 30 are male. In 18 cases, the PRs are from caregiver's family circle, whereas 12 PRs are friends or acquaintances. Among family members, the primary support figure is most often the spouse or partner (n = 9), followed by siblings or other relatives (n = 6), and sons or daughters (n = 3). When the PR is part of the friendship network, in only 4 out of the 12 cases the PR is a member of the same association as the caregiver.

The age of caregivers ranges from 24 to 75 years, with an average age of approximately 55. The age of the PwD cared for ranges from 2 to 64 years, with an average of just over 29. The socio-demographic profiles of caregivers are diverse[12]. The most common educational qualification among the respondents is a high school diploma (13 out of 30), followed by a university degree or master's (n = 9), and non-university postsecondary diplomas (n = 2). CG with lower secondary school education account for the remaining 6 cases.

Despite this relatively high level of education, most of the CG interviewed (17 out of 30) are inactive in the labour market, with the majority of them belonging to the retiree or withdrawn-from-employment categories (n = 8). Among those who are active in the labour market, 8 respondents are salaried workers, 2 are self-employed or engaged in atypical forms of employment, and 3 are unemployed.

In terms of income, 16 respondents report a monthly net family income between €2,001 and €4,000, while 6 report an income above €4,000. The remaining 7 respondents fall within the lower income brackets: 5 report a monthly income between €1,001 and €2,000, and 2 report less than €1,000 per month. These income levels are consistent with recent ISTAT estimates indicating that, in 2023, Italian households had an average net monthly income of approximately €3,125.

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[12] Given the qualitative nature of the study and the limited size of the sample, the data are presented in absolute values.

Table 1. Main socio-demographic characteristics of the dyads and relationship networks in which the CG and the PR are located.

N.	Gender		Age		Caregiver				Relation		Family / parental role of PR	Network size		CG network density	% of aid that PR provides to CG[15]	Consistency of supp. from the network[16]	Network type
	CG	PR	CG	PwD	Area of residence[17]	Qualification	Profession	Net monthly family income	CG-Pwd	CG-PR		Excluding CG	CG included				
1	F	F	24	2	Central	University degree	Private employee	Over 4.000€	Mother	Family	Sister	3	4	0.58	54.55	11	High bonding
2	F	F	57	31	South	Middle school diploma	Housewife	From 2.001 to 4.000€	Mother	Friendship	Friend	4	5	0.5	45.45	11	Low bonding
3	F	M	50	21	South	Master's degree	Precarious worker	I prefer not to answer	Mother	Family	Husband	3	4	0.75	100	4	High bonding
4	M	F	67	60	South	High school diploma	Retired	Over 4.000€	Mother	Family	Daughter	5	6	0.7	25	20	High bonding
5	F	M	65	31	North	High school diploma	Retired	Over 4.000€	Mother	Family	Husband	3	4	0.58	54.55	11	High bonding
6	F	F	66	38	South	High school diploma	Retired	Up to 1.000€	Mother	Friendship	Friend	2	3	0.67	100	4	High bonding
7	F	M	43	15	South	University degree	Private employee	From 2.001 to 4.000€	Mother	Friendship	Friend	5	6	0.8	33.33	9	High bonding
8	F	M	38	9	North	Middle school diploma	Housewife	From 1.001 to 2.000€	Mother	Family	Husband	3	4	0.5	60	10	Low bonding
9	F	F	29	3	South	Middle school diploma	Housewife	Up to 1.000€	Mother	Friendship	Friend	4	5	0.65	37.5	16	High bonding
10	F	M	72	37	North	High school diploma	Retired	Over 4.000€	Mother	Family	Husband	4	5	0.6	50	12	High bonding
11	F	M	32	9	North	High school diploma	Private employee	From 2.001 to 4.000€	Mother	Family	Husband	4	5	0.65	45.45	11	High bonding
12	M	F	69	30	North	University degree	Retired	Over 4.000€	Father	Family	Wife	3	4	0.58	66.67	9	High bonding
13	F	F	46	6	North	High school diploma	Unemployed	From 1.001 to 2.000€	Mother	Friendship	Friend	3	4	0.42	40	10	Low bonding
14	F	F	67	33	North	High school diploma	Retired	From 2.001 to 4.000€	Mother	Friendship	Friend	3	4	0.58	40	10	High bonding

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[15] Percentage of aid provided by PR to CG out of total aid provided by the network: value obtained from: sum of aid received by CG from PR alone divided by the sum of aid received by CG from all members of the network (including PR). All multiplied by one hundred to obtain the percentage value.

[16] Consistency of the diversity of support received from the network (how much help CG indicated receiving from others). Value derived from: sum of all the different types of help (e.g., money, material aid, information, etc.) that CG received from all members of the network.

[17] The regions have been divided by geographical area based on the Istat classification: North (Valle d'Aosta, Piemonte, Liguria, Lombardia, Trentino Alto-Adige, Veneto, Friuli-Venezia Giulia, Emilia-Romagna), Central (Toscana, Lazio, Umbria, Marche), South and Islands (Abruzzo, Molise, Campania, Calabria, Basilicata, Puglia, Sicilia e Sardegna).

15	F	F	45	8	North	High school diploma	Unemployed	From 2.001 to 4.000€	Mother	Friendship	Friend	4	5	0.55	33.33	15	High bonding
16	F	F	53	18	North	Master's degree	Self-employed	From 2.001 to 4.000€	Mother	Family	Mother	2	3	0.5	100	10	Low bonding
17	F	M	52	18	South	Middle school diploma	Housewife	From 2.001 to 4.000€	Mother	Family	Father	2	3	0.5	100	6	Low bonding
18	F	M	75	49	South	Tertiary diploma	Retired	From 2.001 to 4.000€	Mother	Family	Son	3	4	0.5	45.45	7	Low bonding
19	F	M	45	19	Central	Master's / old system / specialist degree	Private employee	Over 4.000€	Mother	Family	Brother	3	4	0.42	40	12	Low bonding
20	F	F	32	56	South	University degree	Student	From 2.001 to 4.000€	Mother	Friendship	Friend	2	3	0.67	100	6	High bonding
21	F	M	53	49	South	High school diploma	Public employee	From 2.001 to 4.000€	Sister	Family	Husband	3	4	0.58	85.71	14	High bonding
22	F	F	71	33	North	Middle school diploma	Retired	From 2.001 to 4.000€	Mother	Family	Daughter	3	4	0.58	41.67	6	High bonding
23	F	F	67	64	South	Middle school diploma	Housewife	From 2.001 to 4.000€	Cousin	Family	Cousin	2	3	0.5	100	16	Low bonding
24	F	M	60	35	South	High school diploma	Private employee	From 2.001 to 4.000€	Mother	Family	Husband	4	5	0.55	28.57	14	High bonding
25	F	M	70	42	South	High school diploma	Housewife	From 2.001 to 4.000€	Mother	Family	Husband	2	3	0.5	100	6	Low bonding
26	F	M	58	35	South	High school diploma	Employee	From 1.001 to 2.000€	Mother	Friendship	Associative circuit	N/A	N/A	N/A	0	16	Low bonding
27	F	F	56	47	South	High school diploma	Unemployed	From 1.001 to 2.000€	Sister	Family	Sister	N/A	N/A	N/A	0	1	High bonding
28	F	F	58	24	South	University degree	N/A	From 2.001 to 4.000€	Mother	Friendship	Associative circuit	N/A	N/A	N/A	60	5	Low bonding
29	F	F	62	28	South	Tertiary diploma	Worker	From 2.001 to 4.000€	Mother	Friendship	Associative circuit	N/A	N/A	N/A	60	5	Low bonding
30	F	F	59	27	South	University degree	Private employee	From 1.001 to 2.000€	Mother	Friendship	Associative circuit	N/A	N/A	N/A	100	3	Low bonding

The vast majority of observed CG–PwD dyads consist of mother–child pairs (n = 25) and, less frequently, father–child pairs (n = 1). There are also cases of spousal caregiving relationships (n = 1) and other kinship-based relationships (n = 3). This data highlights that caregiving relationships are strongly feminised and internalised mainly within the family structure.

The caregiver's social support network is relatively small, averaging 3.16 individuals (mode = 3), ranging from 2 to 5. The network density[1] ranges from 0.4167 to 0.8000, with an average of 0.5764. These figures indicate small but cohesive networks, characterised by high relational intensity and frequent overlap among support figures.

4. Results

4.1. "Perpetual parents" and the pervasiveness of care relationships

A central theme emerging from the dyadic interviews is that of "perpetual parents" (Kelly & Kropf, 1995) – the experience of a parenthood that extends indefinitely over time and remains totalising even when the person with a disability (PwD) reaches adulthood.

Considering the caregivers' age groups (up to 44 years; 45–64 years; 65–74 years), three main categories of CG–PwD dyads can be identified based on their average age: (a) caregivers aged around 33, caring for PwD aged around 16; (b) caregivers aged around 54, caring for PwD aged around 26; and (c) caregivers aged around 69, caring for PwD aged around 42.

In most cases, these are mother–child relationships. Identified with the parental bond, the caregiver's role takes on a "perpetual" character that exceeds the normative boundaries of conventional parent–child relationships. Typically, even within the so-called "extended family of the young adult," dependence on the family of origin tends to decrease over time. Moreover, as parents age, the direction of caregiving is usually reversed, with adult children caring for their elderly parents. In our sample, however, the continued dependence of children on parents means that the caregiving relationship coincides with the parental relationship. The reciprocal redefinition of parental and caregiving roles within this dyadic relationship both influences and is influenced by the structure of the formal and informal support networks in which the dyad is situated.

In nearly all cases observed, caregivers look after PwD with congenital or early-onset conditions, in some cases diagnosed at birth and in others after a

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[1] Network density refers to the CG network - Range: 0-1; 0 = no links between nodes; 1 = all nodes are connected to each other.

complex and prolonged diagnostic process. Only two cases involve acquired disabilities. The most frequent conditions include autism spectrum disorders (moderate to severe, $n = 11$), cognitive impairments (moderate to severe, $n = 7$), and Down syndrome ($n = 4$). Other conditions reported include spastic tetraparesis, motor disabilities, cerebral palsy, amyotrophic lateral sclerosis (ALS), and developmental disorders. In many cases, PwD experience multiple limitations simultaneously.

For most parents, the diagnosis of their child's disability occurred in the early months or years of life, often after noticing developmental deviations from expected norms. Several caregivers describe the moment of diagnosis as a shock followed by a long process of relational and emotional adaptation: "*At the beginning, the shock of realising that you will spend your whole life caring for a disabled daughter, with all the worries about her future, is very strong. Now, even though it is hard, it has become a habit*" (CG 25). Others use military metaphors to describe their adjustment process: "*Like any mother, it was a cold shower. I gathered my strength with the help of those close to me who love me. I told myself, 'If I give up, I will not win this battle"* (CG 09).

Interestingly, many parents do not explicitly acknowledge taking on a different role. The extensive effort required to address the daily needs of the PwD is perceived as an intrinsic part of parenthood. One caregiver of two children with disabilities states: "*For me, it is normal to take care of my children. That is what I do – my days are filled with the tasks and challenges of caring for [NamePA]*[2] *and his brother. In our family, we try to divide tasks as best we can: I take care of the children, my husband takes care of work*" (CG 17).

Even when care extends throughout life, caregiving is viewed as an integral dimension of both parental and family relationships. In one case, after the birth of a fourth daughter with Down syndrome, the mother experienced a depressive episode, and her 14-year-old eldest daughter assumed the caregiver role: "*As the eldest, I tried to take on all the family responsibilities, but it was a time of deep anguish and pain, I will be honest*" (CG 27). Now an adult, the same daughter continues in that role.

Care relationships are described as all-encompassing, occupying the caregiver's daily time and emotional energy. The more severe the disability, the more the caregiver's commitment is described as pervasive and non-delegable, encompassing multiple simultaneous activities: "*On weekdays, about two hours; on weekends and holidays, even more – hygiene, meals, walks…*" (CG 12). "*My personal commitment consists of assisting him in all his concrete daily needs*" (CG 17).

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[2] The term NomePA, in accordance with anonymity, refers to the assisted PwD that the CG cares for. This will be the case for all citations in the text.

Care is described as continuous and uninterrupted, often extending into the night: "*In the evening, I have to help her wash, then change her, and put her to bed. However, it does not end there – she will definitely wet herself, so I have to change her again… and then it all starts again in the morning*" (CG 10). This daily cycle repeats year after year, even when the child becomes an adult. Another caregiver says: "*It has affected me deeply – my life stopped. I have become completely symbiotic with her; she became the centre of everything*" (CG 15). This continuous investment of time and emotion produces a kind of absorption into care activities that also has an identity dimension: "*Out of 24 hours, I take away six for myself – the rest is all for him. My time revolves around [NamePA]; he comes first, then everything else. I live for him*" (CG 26).

In such cases, the boundaries between caregiver and PwD seem to collapse, creating a symbiotic and fusion-like relationship that, as noted in the literature, carries risks of loss of self (Aksamit & Mar Badia Martin, 2021). Within this framework, the parental relationship is pervasive, continuous, and totalising (see Table 2).

Table 2 - Characteristics of the parental caregiving relationship with people with disabilities.

Dimension	**Description**	**Qualitative Example**
Pervasiveness	Continuous and comprehensive presence of the caregiver in all aspects of the PwD's daily life	"*All day, from when I wake up to when I go to bed, is dedicated to him*" (CG 28)
Continuity	Uninterrupted daily commitment, including at night	"*Then it all starts again in the morning*" (CG 10)
Totality	Complete identification with the care role and absorption of personal identity	"*I live for him*" (CG 26)

Even accounting for varying degrees of disability severity, this pervasive, continuous, and totalising care relationship supports the hypothesis that caregiving – particularly in cases of severe or complex limitations – is not merely a set of caring practices but rather a distinct relational model characterised by interdependence between CG and PwD (Bengtson et al., 2011).

This model shapes caregivers' biographical trajectories, significantly constraining their employment and social interaction opportunities. At the same time, the opportunity constraints faced by CG fall back and turn into constraints for PwD. This statement is empirically grounded in caregivers' accounts, which show how constraints in caregivers' biographical choices are directly translated into limitations for persons with disabilities. In particular, employment decisions structure the everyday lives of PwD. As one CG explains, "*I had to decide not to pursue a career, to refuse going abroad when they asked me, because with her it was impossible*" (CG 23). Here, the CG's renunciation of professional mobility becomes a necessary condition for maintaining the care arrangement, thereby shaping the PwD's living conditions. Similarly, restrictions in caregivers' social and spatial availability produce confined experiential worlds for PwD: "*She doesn't go out very often (unfortunately, we only take her out when strictly necessary)*" (CG 25). In these narratives, CG' opportunity constraints do not remain individual sacrifices but are structurally converted into constraints that delimit the social participation, mobility, and daily experiences of PwD.

4.2. The effects of care work on caregivers' well-being

The caregiving experience has a profound impact not only on the professional trajectories of caregivers but also on their psychological and physical well-being and, more broadly, on their overall quality of life. The intensity of the care commitments required by a person with a disability (PwD) often makes it impossible to reconcile caregiving with full-time employment for both parents: "*It is absolutely impossible for both of us to work. Only one of us can. Both? Impossible. There are therapy sessions at impossibletimes, a lot of medical appointments, hospitalisations… It is just not feasible to have a job alongside this. I would have to leave her in someone else's care 24/7"* (CG 01).

In other cases, those who were previously employed have had to leave their jobs entirely:

"*I used to teach. Then, with my other daughter too, I had more than one job. But I quit teaching to spend more time with my disabled daughter*" (CG 06). "*I had to decide not to pursue my career, to refuse assignments abroad when I was asked, because with her it was impossible. Eventually, I resigned from my previous job*" (CG 22).

Some caregivers opt for part-time employment to make work compatible with caregiving responsibilities, such as administering medications: "*I also chose to work part-time, only three hours a day, because [NamePA] takes medication five times a day. So early in the morning, right after breakfast, before I leave, I have already given two rounds of meds. After lunch, there is another, then one in the evening, and one more before bed*" (CG 29).

In other cases, the decision to reduce working hours stems from the lack of shared responsibility within the household: "*I am basically alone, at least for the practical side of things. That is just how it is in our family – all of [NamePA]'s needs fall on me. My husband is reluctant and struggles to help. Professionally, too, I had to give up a full-time job and settle for part-time work*" (CG 19).

Across the interviews, caregivers recount stories of sacrifice, exhaustion, and long-term stress. Sometimes, leaving work is driven not only by the PwD's needs but also by the caregiver's health conditions. In other cases, it is a preemptive decision, given the impossibility of finding compatible employment: "*Even if I wanted to work, it would be impossible to find a job with hours that fit around [NamePA]. When you go to a job interview and start saying, 'I cannot work in the afternoons or before 8 a.m. because I have to get [NamePA] ready and take him to school…' it becomes almost impossible to get hired*" (CG 08).

Caregivers often describe a state of permanent alertness and emotional fatigue associated with managing complex or potentially critical health situations: "*We are sick too, in a way… There is always this constant state that keeps me from being calm. At first, the stress was so intense that I would wake up suddenly at night, running to check on her because I thought I heard something. You cannot sleep*" (CG 04). Caring for a PwD can also lead to social isolation and a deep sense of loneliness, as illustrated by a caregiver looking after her autistic sister: "*My general life situation is a disaster – not that [NamePA]'s health is to blame. Nevertheless, since our parents passed, I have been completely alone. It has gotten worse; I have no life of my own. My sister's condition does not allow it*" (CG 20).

The adverse effects of caregiving can also extend to persons of reference (PRs), as one daughter assisting her mother in caring for an autistic sister recounts: "*When you have an autistic person at home, the dominant feeling is helplessness. Moreover, helplessness turns into frustration and depression. I have been depressed too – maybe my school absences were a way of protesting, since I could not express it verbally. I understood the problem was huge, and you implode*" (PR 22).

However, alongside fatigue and distress, caregivers also express symbolic and emotional forms of gratification: "*It is exhausting, but seeing him calm and happy makes up for everything" (CG 21). "It is very hard… I have to plan even just to go to the cinema… but when he smiles, I am happy too"* (CG 28).

This emotional ambivalence supports the idea that caregiving is experienced simultaneously as a sacrifice and a source of meaning: "*Even when the day has been completely dark, something small happens, and I focus on that. Maybe I am not very reliable when I say this, but I always tell myself that if there is anything good in me, it is thanks to this experience*" (CG 26).

The caregiving relationship thus emerges as a dense moral space, in which the caregiver constantly negotiates their sense of self, social and familial expectations, and the recognition of their role. This identity dimension is crucial to understanding the socio-relational nature of care, which is not merely a form of service provision but also a biographical and emotional reconfiguration. Despite the difficulties, when caregivers can rely on social support networks, care relationships can become emotionally rewarding and even sources of joy: "*Of course, having a 42-year-old disabled daughter is not easy to manage in family life. However, it is also true that [PR] is retired, and I can dedicate myself to my daughter full time – and I do it gladly, without feeling it is too much of a sacrifice"* (CG 25).

In sum, caregiving affects not only the caregiver's physical and psychological condition but also their identity, social connections, and life possibilities, intertwining suffering with resilience, duty with affection, and fatigue with meaning.

4.3. The role of the person of reference

One of the most significant findings of this study concerns the figure of PR, identified by CG as a key node within their support network. In most of the cases examined, the PR coincides with a cohabiting family member. However, in other situations, the PR may be a sibling, a non-cohabiting partner, or an external figure such as an educator or communication assistant.

In many cases, parental dyads manage to cope through shared responsibility and mutual support. A husband (PR) assisting his wife (CG) reports that, despite the challenges, their relationship has grown stronger: "*At first, it was like a lightning strike – it changed our lives completely. But over time, by supporting each other, we managed to find balance again"* (PR 11).

In some situations, caregiving is not centred on a single individual but rather on the relationship itself, as a cooperative dyad (CG and PR) that becomes the axis around which broader networks of support can form, including professionals and volunteers. As one PR explains: "*We have always been our daughter's main caregivers. Over the years, we have had some volunteers help with rehabilitation therapy, but we remain the central point of reference. Everything else revolves around us*" (PR 5). This same PR underlines how, even with external help, the spousal dyad remains the emotional and operational core: "*Everything around us helps – the home care assistant, the lady from Sri Lanka who helps with housework – but we are still the protagonists of this story. The caregiver role is there, and we share it equally*" (PR 10).

Beyond the division of tasks, some caregiving relationships exhibit mutual interdependence, as in the case of a father (CG) and daughter (PR) caring together for their wife/mother with ALS: "*We rely on each other – if dad is not here, I cannot manage certain things; if I am not here, there are things he cannot do either*" (PR 04). This mutual trust and role interchangeability can become so strong that PRs effectively act as functional substitutes for the CG. A wife helping her husband (the primary caregiver) puts it: "*We do everything together, and when he is not here, I take his place, of course*" (PR 12). In some cases, such as those just highlighted, the roles of CG and PR seem interchangeable.

This transferability of roles (to someone younger than the CG) represents what might be termed a form of "relational inheritability" of care – the possibility that someone else may assume caregiving responsibilities in the future. This offers caregivers a measure of emotional security, especially when that "someone else" is part of the same family. As one CG explains: "*When parents die, there are always problems. Even if you have raised your children to understand that their sister is not well, you know how it goes when the mother is gone… However, I do not see a dark future for [NamePA]. I am calm, because she has two brothers and a sister*" (CG 18).

Several caregivers express similar hopes, though coupled with concern about not burdening others: "*I have sometimes sacrificed things for myself because I would rather prepare her well for the future – I don't want her to be a burden for her brother or my sister*" (CG 30).

Even when PRs are not family members, caregiving relationships can evolve into deep bonds of trust and emotional closeness, often described in familial terms. For instance: "*[PR] is really like my husband – the male figure missing from our household. He is a practical, emotional, and psychological support for both me and my daughter*" (CG 07). "We have developed a real bond – [PR] feels like the sister I never had" (CG 15).

Social support relationships often acquire familial value, not only for caregivers but also for PRs themselves: "*It has brought us so much closer. I have another sister now*" (PR 13). In some cases, PRs act as structural substitutes for caregivers: "*For me, [PR] is the person most prepared to replace me, because she knows [NamePA] best and gets along with her the most*" (CG 15). A caregiver who looks after her sister in "complete solitude" describes her neighbour (PR) as: "*Another sister, the one who really helps – I call her my 'sister-sitter'*" (CG 20). However, in other situations, such role fungibility is impossible: *"[PR] cannot step in where I have to intervene myself*" (CG 20).

Table 3 - Main dimensions of the social support role of PR.

Type of Support	Description	Example
Emotional	Emotional containment, empathy, and companionship	"*She is the sister I never had*" (CG 15).
Practical–everyday	Concrete help with daily routines, a temporary substitution for the caregiver	"*He gives me time to focus on my own needs and commitments*" (CG 19).
Technical–professional	Mediation with services, specialised skills, and professional advice	"*She reassures me scientifically and practically about what is happening*" (PR 01).
Mixed	Integration of multiple dimensions over time	"*He is our reference point — practical and psychological at the same time*" (CG 07).

The role of the PR can thus be articulated along three main dimensions – emotional and moral support, practical and everyday assistance, and technical-professional support – often intertwined in practice (see Table 3).

As these excerpts highlight, the relationship between CG and PR is based on trust: PR primarily acts as a central hub within the support network.

Care and social support relationships thus extend beyond merepractical care: not only within family-based networks but also across friendship and professional ties.

The sociological significance of this lies in the fact that, where trust is present, caregiving relationships – even family-based ones – can expand into wider support networks, allowing for a partial redistribution of material, emotional, and symbolic burdens.

Whether familial or not, these trust-based relationships become increasingly vital as confidence in public services declines.

4.4. "The island that doesn't exist": the difficult relationship with public welfare services

From the interviews, a widespread distrust of public welfare services clearly emerges. Many CGs describe the social and health care system as fragmented, bureaucratic, and slow, characterised by a lack of continuity and inadequacy in meeting the complex needs of PwD. Where trust does exist, it tends to be directed toward individual professionals – such as doctors, educators, or therapists – rather than toward institutions or structures as a whole.

A first source of distrust lies in the absence of available services and reliable information on how to access them: "*They simply do not exist where we live*[3]. *It is hard not only to get what you need but even to know who to talk to. Institutions do not help at all*" (CG 20).

Some respondents believe that this lack of information is intentional, a means of reducing demand: "*No one tells you anything. Parents only learn through associations, through the networks they create among themselves. The institutions are happy to keep you uninformed – it saves them money*" (PR 03). Another CG adds: "*I always have to be the one to look for help. They are not available. I have not had good experiences with them"* (CG 13).

This situation is echoed in the experience of a caregiver looking after her sister with Down syndrome: "*We have tried to get information about helpers who could stay with [NamePA] and our mother for a few hours a day, but you have to get on a waiting list. After a while, we just gave up – it is easier to do everything ourselves"* (CG 27).

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[3] The CG is located in the southern part of the country.

Even when caregivers begin the application process for support services, they often describe the procedures as cumbersome and discouraging, undermining their faith in the system: "*There is too much bureaucracy when you are already dealing with a disability. You can't keep putting up barriers for people who are just trying to claim a right they already have*" (PR 22).

Another PR adds: "*It should not be like this – it is a right, something that should be granted. Instead, it feels like you have to beg for a favour, as if they are doing you a kindness to recognise what is already yours*" (PR 04). As one caregiver summarises: "*Our experience with the services has been terrible. You cannot trust them. That is why I do not rely on anyone anymore. Bureaucracy makes everything painfully slow*" (CG 17).

Even for those who manage to access health or social services, the support provided is often insufficient for both the PwD and the CG. A daughter assisting her father in caring for her mother with ALS explains: "*We get visits from nurses and a physiotherapist, yes – but honestly, we expected much more. The nurse comes, checks her blood pressure, makes sure the catheter is okay, and leaves in 20 minutes. Then they come back two or three days later*" (PR 04).

There are, however, a few positive exceptions, with some caregivers expressing satisfaction: "*[NamePA] attends a Day Centre, and our relationship with the staff there – both ours and hers – is really excellent*" (CG 12).

Reducing financial assistance can have severe consequences for families managing long-term or high-intensity care needs. One PR describes how changes to a regional care allowance created new hardships: "*It was originally for ALS patients, and we managed decently with it. However, then it was cut from €1,500 to €1,000 – and the care hours were completely eliminated. We even took legal action after being suddenly left without any support. It was only after media coverage that the authorities contacted us again*" (PR 23).

Another caregiver recalls the effort required to secure home care assistance from the municipality – only to discover that the staff lacked training: "*I always had to train the people they sent. They had no idea about specific therapies or ABA techniques, or augmentative communication methods*" (CG 29).

In most cases, PwDs cannot manage their relationships with services independently, requiring the continuous mediation of the caregiver: "*When she needs to renew her therapy plan, the process is so complicated that she could not possibly do it on her own. Even just getting medication is exhausting. Physical therapy? It has been cut for everyone – no more home sessions. Everything is becoming more complicated. Living independently would be impossible*" (CG 21).

For many caregivers, these problems are not due to individual incompetence but to systemic deficiencies: "*The issue is not the people, it is the system. [NamePA] should be entitled to at least ten psychomotricity sessions a year; the last was in June 2023, and the next is in June 2024*" (CG 15).

The COVID-19 pandemic further exposed these structural weaknesses. Many caregivers describe having felt completely abandoned during lockdowns: "*During COVID, no one checked in – not a single phone call. We were stuck 24/7 at home with a child with a diagnosis… completely abandoned by the system. They give you the diagnosis and say, 'Good luck'*" (CG 08).

Others, however, report positive experiences with certain local health services during the same period: "*When [NamePA] got COVID, the service was actually good – they came to the house, they were attentive. The doctors were young and professional*[4]*, and I felt safe because they were really there for us*" (CG 21).

Some caregivers highlight the importance of individual professionals who go beyond their formal duties: "*At the local health unit, I found a supervisor who really cared about our situation. Even though she had many patients, she followed up personally and even went to the school to do supervision sessions*" (CG 09). Others praise the social services, emphasising the quality of personal relationships: "*I can only speak well of social services. Thanks to them, we have a home educator and music therapy for my son. Since he is not independent, we also have an assistant for autonomy at home*" (CG 11). "*Social services work only if you are lucky enough to find well-prepared staff. In our case, we were fortunate, and a real friendship developed beyond their professional role*" (PR 10).

The pandemic thus highlighted a broader phenomenon: while many caregivers and PRs express deep institutional distrust, they often maintain strong personal trust in individual professionals. What determines trust or mistrust is not merely technical competence, but rather the attitude of attention and empathy professionals show toward both the PwD and the caregiver's demanding life circumstances (Beach et al. 2021)

Some caregivers, frustrated by the absence of autism-related services, took matters into their own hands: "*There were no autism services thirty years ago – none twenty years ago, barely any ten years ago. There are some now, but they are still insufficient. We needed places where families could take a break. So I kept fighting, going to every office I could, until I created services myself, which were later accredited by the health system and the municipality*" (CG 22). Several participants belong to associations active in the disability field – some of which they themselves helped found. These associations enable families caring for disabled children to connect and support one another, forming communities of mutual help and empowerment: "*I found great friendships among other mothers in similar situations – really amazing women who gave me courage and helped rebuild my self-esteem. At first, I used to think I was not doing anything worthwhile. Now I see I have done a lot*" (CG 28). For others, the association functions almost like a surrogate family: "*Without them, I would be lost. I hardly meetanyone here. For me, they are like a family – I can call Sabrina or Manu anytime. They have more experience than I do in handling difficult situations*" (CG 30).

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[4] The CG is located in the southern part of the country.

Associations thus foster trust and social support and fill institutional gaps. As one PR observes: "*If it were not for private*[5] *associations organising activities for these kids, there would be nothing*" (PR 07). Speaking of the caregiver she supports, the same PR adds: "*She opened a cooperative to help other parents, too. She is a leader – driven by love for her son and for kids like him"* (PR 07).

A recurring theme is the desire to help other families in similar circumstances: "*I have been part of three associations over the past fifteen years, even as a board member, always trying to support other parents – in WhatsApp groups, phone calls, in person*" (CG 03). This help goes beyond information-sharing; it extends to practical solutions such as the creation of time banks or cooperative projects. When these initiatives succeed, they become vital reference points for families. However, caregivers lament the absence of what one calls *"the island that doesn't exist"*.

"*What we are missing – what we call 'the island that does not exist' – is the future. Right now, [NamePA]'s situation is perfect; he is in a wonderful routine. Nevertheless, we constantly ask ourselves: what will happen when we are gone? If only this centre could magically become a living environment for him in the future, I would walk to Lourdes to thank God. That is the real problem – it is all about the present*" (CG 14).

The thought of the future, the so-called *"after us"* (when parents are no longer there), dominates many caregivers' concerns: "*We need to find people who will care for our children when we cannot, but consciously, with proper preparation. We did not start soon enough to train people to stand beside them when we are gone*" (CG 26). Others envision a network of services enabling parents to help their children achieve self-determined lives: "*We need a network that lets parents do what their children want to do. Furthermore, when they cannot express it, parents should act as their voice. That would be a great step forward – but only if there are skilled, empathetic people who really know how to work with them"* (CG 29).

Some even propose creating a "civic network of care" for their children's future. One caregiver articulates this vision eloquently: "*It cannot just be parents or family caregivers bearing this immense burden alone. That is not fair to the person with a disability, nor to the caregiver. Civil society must share this responsibility. If it is spread across a wider network, the load becomes much lighter. I used to think no one could replace me, but then I realised – if you break down what I do into many small parts, maybe a hundred people could each take a piece of it, coordinated by social services, within an organised life project"* (CG 16).

This perspective envisions a transition from family-centred caregiving to a distributed model of collective care, in which social support networks draw on the community's social capital.

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[5] For the sake of fairness, here the term private associations refers to third sector organizations.

4.5. Bonding and bridging social capital

The support networks of the CGs involved in this study are predominantly characterised by bonding social capital – that is, by strong intra-family and friendship ties that provide emotional, material, and practical assistance. This type of social capital generates cohesion and trust, yet it can also lead to relational dependence and social closure.

In many cases, caregivers describe a support system in which siblings, spouses, or close friends play significant and ongoing caregiving roles. The family thus emerges as the primary network that sustains the care burden, functioning as the main safety net compensating for the absence of institutional support. However, within this broad bonding framework, it is possible to distinguish between two configurations: *high-bonding networks*, where relationships are very dense and interdependent, and *low-bonding networks*, where ties remain strong but less pervasive and more open to external influences.

This differentiation was operationalised using network density as a proxy for bonding strength (Tronca, 2007): networks with a density value between 0 and 0.5 were classified as *low bonding*, while those with values between 0.51 and 1 were considered *high bonding*.

The analysis shows that caregivers in low-bonding networks receive, on average, 7.92 instances of support from their network members in the last 12 months, while those in high-bonding networks receive, on average, 10.12. When focusing specifically on the support provided by the PR, both groups report similar figures – about 4 instances of help on average (4.23 for low-bonding vs. 4.7 for high-bonding networks).

However, when considering the percentage of total support provided by the PR within each network, a pattern emerges: PRs in low-bonding networks contribute a larger share of total support (65.45%) than those in high-bonding networks (52.73%). This suggests that, in more cohesive networks, caregiving responsibilities are more evenly distributed among several network members. In contrast, in low-bonding networks, the PR tends to shoulder a greater burden of assistance.

Alongside bonding relationships, the study also identified – though in smaller numbers – examples of bridging social capital. Bridging capital arises when caregivers or PRs establish links with external networks[6], such as associations, educational institutions, health care services, or professionals, thus connecting the family unit to broader relational systems. As one PR explains: "*I*

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[6] The network analysis revealed that they mainly emerged with family members or members of ETS, while links with professionals emerged from the dyadic interviews to a lesser extent than the former.

coordinate with the ABA therapist and the supervisor to create the tightest network possible around [NamePA]" (PR 09).

In such cases, the caregiving network is no longer purely private or domestic; it becomes hybrid, integrating informal and formal connections. These networks negotiate resources, expertise, and recognition across family and institutional boundaries. However, the findings show that bridging capital remains fragile and unsystematic. It largely depends on caregivers' initiative and relational skills rather than on structured institutional frameworks. As a result, bridging relationships often lead to high variability and inequality in access to support and resources – differences that can significantly affect both caregivers' well-being and the life opportunities of PwD.

Table 4 - Types of social capital present in family caregiving networks of people with disabilities.

Type of Social Capital	**Primary Source**	**Main Effects**
Bonding	Family ties, stable affective networks, "chosen family"	Emotional and practical support; risk of relational closure and caregiver overload
Bridging	Associations, educators, social and health professionals, and service providers	Access to external resources and institutional recognition; fragile and uneven networks

In summary, the caregiving networks observed in this study display high internal density (bonding) and, in some cases, limited external openness (bridging). This prevalent relational configuration provides stability, trust, and continuity, but at the same time reinforces closure and the concentration of care responsibilities on the caregiver.

While bonding capital ensures reliability and intimacy, the lack of bridging ties can hinder the institutional visibility and social sustainability of care. The findings therefore suggest the need for policies and community practices capable of strengthening bridging mechanisms, transforming caregiving from a private obligation into a collective social process shared across families, professionals, and civic institutions.

5. Discussion

The qualitative analysis of CG–PR dyads clearly demonstrates that caregiving for PwD is not merely a set of practical or assistive tasks, but a complex relational system that profoundly shapes caregivers' identities, emotions, and social relationships. The findings underscore how the care relationship assumes a totalising character – occupying the caregiver's entire life space and redefining time, affective bonds, relationships, and even the relationship with the self.

The experience of "perpetual parents" expresses the continuity between ordinary parenthood and lifelong caregiving, in which the time of motherhood or fatherhood never ends. The relationship with the PwD becomes a continuous relational process: "*All day, from when I wake up to when I go to bed, is dedicated to him*" (CG 28). These words capture a relational model in which the time of care has no interruption – a continuum that, over the years, evolves into what Bengtson et al. (2011) call linked lives, in which the caregiver's and the PwD's lives are profoundly interdependent. It is therefore unsurprising that many caregivers describe themselves as "living for" the person they care for (CG 26) or say that their own life has stopped (CG 15). These expressions reflect a functional and emotional symbiosis that, while strengthening affective reciprocity, also narrows the caregiver's space for autonomy and self-realisation. This fusion between identity and role recalls Finch and Groves' (2022) reflection on the morally ambivalent nature of care: it is both a gesture of responsibility and love and a form of internalised duty embedded in cultural expectations. Many caregivers describe their condition in terms of a "normality of sacrifice": "*For me, it is normal to take care of my children. Every day is filled with their needs*" (CG 17).

Care thus becomes a biographical norm rather than a temporary commitment. The dimension of sacrifice is internalised as a natural component of the self. CGs report chronic stress, social isolation, and economic strain—for instance: "*It is absolutely impossible for both of us to work… I would have to leave her with someone 24 hours a day*" (CG 01). At the same time, they recognise care as a source of meaning and personal growth: "*It is exhausting, but seeing him happy makes up for everything*" (CG 21). This dual experience of burden and fulfilment shows that caregiving is both a space of constraint and a space of meaning. On this site, caregivers continuously negotiate between obligation and affection, limitation and resilience.

Importantly, the strain of care is not merely physical or emotional but also symbolic. It reflects a mismatch between personal recognition and social recognition: caregiving, though essential, remains largely invisible and undervalued (Bell et al. 2019). The vulnerability that emerges is therefore not only individual but systemic. The ambivalence of care – between dedication and exhaustion, meaning and marginalisation – constitutes a structural tension of family caregiving that cannot be resolved through material support alone; it requires a cultural and institutional revaluation of the caregiver's social role.

A distinctive contribution of this study lies in its focus on the person of reference (PR) as a crucial element of the caregiving network. The PR acts as a trust-based node, redistributing – at least partially – the material, emotional, and symbolic burden of care. In some cases, the CG–PR relationship forms a cooperative dyad, as in the example of a father and daughter caring together for a mother with ALS.

The PR's social support functions manifest along multiple dimensions: emotional support ("*She is the sister I never had*", CG 15), practical assistance ("*He gives me time to focus on my own needs*", CG 19), and technical or professional mediation ("*I coordinate with the ABA therapist and supervisor*", PR 09).

Over time, the PR often becomes a broker (Burt, 2005) linking the caregiver's family network with external social and professional systems, thus broadening access to resources, knowledge, and legitimacy. When consolidated, this trust-based relationship produces what might be termed "relational inheritability" – the possibility that care responsibilities can be shared, delegated, or transmitted over time. However, in most cases, this inheritable form of support remains confined within the family, highlighting a persistent endogamic closure of caregiving networks.

The interviews reveal an ambivalent relationship with public services: caregivers express widespread distrust toward welfare institutions but trust and gratitude toward individual professionals who demonstrate empathy and proximity. This asymmetry reflects the fragmentation of public welfare systems and the lack of institutional reliability. In response, caregivers and PRs often engage in self-organisation through associative networks that serve as spaces for mutual aid and civic participation.

These associations rebuild trust, belonging, and collective competence, transforming caregiving from a private duty into civic engagement. They represent embryonic examples of what could be called "relational welfare" – a model in which families, professionals, and communities co-produce care practices and social solidarity.

However, these experiences are often episodic and unequal, depending mainly on individual initiative and local resources. The prevalence of bonding social capital – dense, closed, and family-centred networks – ensures reliability and emotional security but also reinforces isolation and overload. The scarcity of bridging ties with external actors (institutions, professionals, and associations) limits the institutional recognition and sustainability of caregiving practices.

Consequently, caregivers' social worlds are structured by a paradox: the same networks that sustain them emotionally also isolate them structurally. Bonding networks provide intimacy and resilience but confine care within private, invisible spaces; bridging networks, though scarce, represent potential channels of emancipation – pathways to recognition, redistribution, and shared responsibility.

In this light, caregiving emerges not merely as an individual act but as a relational production of social capital. This process generates meaning, cohesion, and solidarity, while simultaneously exposing caregivers to vulnerability. It occupies a hybrid position between family solidarity and institutional substitution within welfare systems that increasingly delegate care responsibilities to households.

The figure of the PR exemplifies this dynamic: as co-custodian of care, the PR acts as both emotional infrastructure and potential link to the community. In contexts where public trust erodes, these micro-level relationships constitute the social fabric of everyday welfare.

Finally, the emergence of bridging social capital in some cases suggests a more distributed and collective model of care, in which responsibility does not rest solely on the caregiver. However, it is shared among families, professionals, services, and civil society. As one caregiver insightfully put it: "*There will never be one person who does everything the caregiver does, but there can be a hundred people, each taking a small part, coordinated by social services in an organised life project*" (CG 16).

This quote encapsulates the transition from individualised caregiving to a shared, distributed model – a vision of care as a collective social infrastructure, rather than as an invisible private burden. Although this study has advantages linked to the use of social network analysis, it also has some limitations: the first is that it only refers to caregivers who have at least one reference/support person; Another limitation is that the analysis focused on the CG network but not on the PR network, if any. A further limitation was that the survey did not include PwD involved in empowerment projects due to the research group's difficulty in accessing this field.

6. Conclusions

The analysis of CGs support networks shows that care is far from being a purely private matter; rather, it constitutes a relational field in which roles, boundaries, and responsibilities are constantly negotiated and redefined. Within this perspective, caregiving can be understood as a "relational good" (Donati & Solci, 2011) – not simply an individual act of "doing," but a form of "being in relation", a condition of interdependence that generates meaning, identity, and social capital.

The concept of the relational good enables us to interpret care not only as a functional or technical task but as a social process embedded in the web of relationships surrounding the caregiver. Caregiving should therefore not be analysed solely at the level of the individual caregiver but within the social network in which that person operates.

From this standpoint, the caregiver is not merely someone who assists, but the central actor of an affective and symbolic network that sustains the everyday life of the PwDs. The relationship between caregiver and PR functions as a trust-based node that allows the caregiver to distribute part of the emotional and practical burden, representing a form of social capital accumulated over time – one that can compensate, at least in part, for the lack of institutional support. Consequently, caregiving offers a privileged lens through which to observe contemporary transformations in family solidarity, trust-based bonds, and emerging (though discontinuous) forms of relational welfare.

Overall, caregiving for PwD can be regarded as a "relational welfare laboratory" – a social context in which new forms of solidarity, trust, and social capital are generated from the bottom up. The continuous interaction between CG, PR, PwD, and associative networks reveals that caregiving is not only a response to vulnerability but also a potential space for social innovation, capable of regenerating ties and activating communities.

Neverthless, for this potential to evolve into a proper social infrastructure, reciprocity (CG, PR, PwD, and associative networks) must be institutionalised. This requires public recognition of the role of social networks, supporting, and integrating caregivers' relational work into public welfare policies.

In this sense, caregiving is not merely a welfare or practical care provisions issue – it is an indicator of the social pact's overall cohesion and resilience. The fragmentation and randomness of caregiving experiences highlight the urgent need for a "public coordination" capable of valuing and integrating the relational capital produced from below, to strengthen systems of social support and caregiving within a subsidiary, bottom-up perspective. By acknowledging care as a collective, relational process – rather than an invisible, private burden – societies can move toward a new paradigm of welfare grounded in reciprocity, trust, and shared responsibility.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: PRIN2022 Project Funded by the European Union – NextGenerationEU – PNRR M4C2I1.1. Project: "Social capital as resource of care practice in Italy: Caregiving and social support in pandemic time". University of Molise (Prof.re Fabio Ferrucci) 2022B58JHF – CUP H53D23005750006.

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