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Running Fast, Just to Stay in the Same Place? Social Movements, Political Parties, and the Politics of the Portuguese Informal Caregiver Statute (2015–2019)

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This article examines the political dynamics behind Portugal's 2019 Informal Caregiver Statute (ICS), focusing on how social movements influenced the policy process through political mediation. The statute was prompted by caregiver mobilisation and advanced in parliament by partisan allies, despite initial government resistance. The movement's influence relied on a favourable political opportunity structure, supportive media and public opinion, and the strategic securing of political allies. However, parties integrated the movement's demands with their own, often conflicting, agendas. In the end, key demands, such as caregiver allowances, pension credits for care work, and expanded public services, were only partially fulfilled. The ICS represents a broad yet limited compromise that reinforces the family's role as the main care provider. This shift from 'familism by default' to 'supported familism' may ultimately hinder a transition to 'optional familism', which would frame care as a choice and necessitate a significant expansion of formal public services.

Keywords: care reform; informal carer; social movements; parties; Portugal

Introduction

The provision of care across Europe faces significant challenges amid rapidly ageing populations and a growing shortage of care workers. Despite the vital importance of caregiving for dependent older persons, political recognition of caregivers (most of whom are women) has come only recently, through policies aimed at acknowledging and supporting their work. The growing burden of care needs, Europe-wide pressure to implement coherent care strategies, and advocacy from politically mobilized caregiver movements have created a context conducive to reform.

This context is particularly salient in Southern European countries such as Portugal, where families bear the primary responsibility for caring for older adults, often at great material, physical, emotional, and financial cost. Public care services remain limited, care workers are in short supply, and prevailing cultural norms hinder the de-familialisation of care. Moreover, the sovereign debt crisis and the austerity measures implemented under Portugal's Economic and Financial Adjustment Program (2011–2014) had a significant impact on the healthcare and social protection systems. These included cutbacks, tightened eligibility, higher user fees, and stricter means-testing, all of which reduced access and coverage (Guillén *et al.*, 2022). Specifically in the long-term care system, while spending on services delivered by subsidised non-profits remained stable (despite families' reduced capacity to support co-payments during the crisis), cash-for-care

provisions were curtailed, as means-testing was introduced for the care allowance, reflecting broader cost-containment efforts (Lopes, 2016; Da Roit, 2021). These changes increased pressure on informal care just as family caregiving capacity declined, due largely to the emigration of many potential caregivers, especially younger generations.

Against this backdrop, our article seeks to answer the question: to *what extent* and through *which mechanisms* was the informal caregivers' (IC) movement able to influence the policy process leading to the creation of the ICS in 2019? We argue that the movement's partial success in shaping the policy depended on three key factors: a favourable political opportunity structure; the ability to mobilise public opinion, aided by national media; and, crucially, the support of influential allies within the political system, including political parties and the President of the Republic. Nevertheless, while the ICS represents a notable social policy innovation by formally recognising informal care and creating a novel allowance for carers, it falls short of resolving persistent issues concerning both the quality of care provided and the well-being of caregivers themselves.

This article joins the literature showing that long-term care (LTC) systems have not remained a frozen landscape as regards the role of informal care and offers another instance of the reform trend towards explicit or supported familism (Leitner, 2014; Saraceno, 2016). This turn has focused on different types of policy instruments. First, the availability of counselling, training, and education for carers has been reported, for instance, in Austria, Cyprus, Greece, Denmark, and France (Spasova *et al.*, 2018). Second, cash allowances and tax reliefs to support carers (Rocard and Llena-Nozal, 2022: 36–45) have been expanded or introduced, and new schemes recognising social contributions were given to informal carers as compensation for caregiving activity (Le Bihan *et al.*, 2019). Third, leaves from work and flexible working arrangements to allow conciliation between employment and informal care (Colombo *et al.*, 2011: 121–127) have been adopted in Germany and Austria, and similar programmes exist in Italy, France, and England. In these countries, furthermore, more flexibility in working hours for working caregivers has been fostered to facilitate the work/care balance (Le Bihan *et al.*, 2013).

While these valuable studies have advanced the field, they are often less focused on unpacking the underlying causal factors and mechanisms of reform. This forms the basis of our second contribution, both to the broader literature on the impact of social movements on social policy, and specifically to the research on the drivers of reforms supporting informal carers. Existing scholarship has largely emphasised motives such as cost-containment (Pavolini and Ranci, 2008; Gori and Luppi, 2024), support for women's work–care reconciliation (Colombo *et al.*, 2011; Kröger and Yeandle, 2013), cultural norms around intergenerational care (Naldini *et al.*, 2016), and the role of policy transfer (Theobald and Kern, 2011). In contrast, we highlight the role of the carers' social movement in initiating and shaping policy change. While previous research has noted the IC movement's role in mobilising action, articulating demands, and setting the policy agenda (Hanson and Champeix, 2023), less attention has been paid to its capacity to build coalitions with political allies and the mechanisms through which it influences policy outcomes (though see, for example, Yeandle *et al.*, 2012; and Ranci and Pavolini, 2015: 275–277).

Our study of the ICS also sheds light on the overall trajectory of the Portuguese care regime for elderly persons. Is the reform path-dependent, a recalibration or a break from past trends? More specifically, does it represent another step toward the privatisation of care, where the state relinquishes its role as social regulator (Ferreira, 2010)? Does it challenge the near-monopoly of state-funded nonprofits, an arrangement that limits the growth of affordable for-profit services while encouraging for-profit care catered to well-off older persons (Lopes, 2016)? And by supporting informal carers without expanding formal services, does it effectively re-familialise care, revealing how deeply rooted cultural norms can constrain reform (Gil, 2024)? Through this discussion, we highlight the relevance of the Portuguese case to broader comparative debates on care reforms.

The article is organised as follows. The next section first develops a framework for analysing variation across European care regimes as regards the preponderance of state, market, third sector, and the family in the provision mix and the existence of policy support for informal care; then, it situates the Portuguese care regime's defining attributes and the directionality of policy reform over time. Then, we review the explanatory factors for reforms supporting informal carers, making the case for considering the politically mediated impact of the informal carers' social movement. The methods section presents our qualitative research design triangulating differently sourced data. The empirical section provides a case-study of the winding road to the 2019 reform, probing the role of the carers' movement in the policymaking process and analysing the partisan political discourse in parliament. The conclusion outlines the main empirical findings and discusses possible reform paths for the Portuguese eldercare regime.

Types of familism and the Portuguese care regime

Countries vary in how they produce, finance, deliver, and govern care for elderly persons. The concept of a care regime captures patterns of similarity and difference in how responsibilities for care are distributed among the family, the state, the third sector, and the market (Rodrigues and Nies, 2013). The family plays a central role, not only in providing care, but also in shaping the gendered and socio-economic impacts of care work and related inequalities.

One of the main focuses of care regime typologies has been on how public services, cash benefits, and support measures contribute to shifting care responsibilities away from families (mostly, women) as the primary caregivers (for an overview, see Pavolini, 2021, and Simmons *et al.*, 2024). Long-term care policies go well beyond service provision to include time-related measures (e.g., paid and unpaid leave, flexible working hours, part-time work) and financial supports, such as tax deductions, direct payments to caregivers, or cash-for-care schemes. The latter aims to enable users to organise care arrangements by compensating informal carers, hiring caregivers, or purchasing professional (public or private) services.

Le Bihan *et al.* (2019), building on the work of Leitner (2003, 2014) and Saraceno (2010, 2016) on defamiliarisation and care policies, propose a framework that combines two key analytical dimensions: the level of support for informal care and the type of care service provision. We expand the latter to include support for service provision by third sector organisations (TSOs), such as charities, non-governmental organisations (NGOs), cooperatives, and associations, whose contributions to the welfare mix are often overlooked. This typology (in Table 1) allows for a comparative positioning of the Portuguese care regime, considering both its historical development and its evolving policy trajectory over time.

Portugal has consistently been portrayed as a familistic country with a subsidiary long-term care regime, only belatedly recognising it as a distinct social risk (Nies *et al.*, 2013; Saraceno, 2014; Lopes, 2016; Leichsenring, 2021). Countries within the familistic cluster evolved in historical contexts shaped by Catholic social doctrine, particularly the principle of subsidiarity, which

Table 1. A family-centred care regime typology

Support for Informal Care	Type of care service policy			
	Strong Public/ Subsidised Provision	Private Non-Profit Providers (TSOs)	Private For-Profit Providers	Weak or No Service Provision
Policy Support for Informal Care	Optional familism	Optional familism via TSOs	Optional familism via market	Supported familism
No Policy Support	De-familisation via the state	De-familisation via TSOs	De-familisation via market	Unsupported familism

Source: Adapted from Le Bihan, Da Roit and Sopadzhyan (2019).

assigns care responsibilities to families, communities, third sector organisations, and other local institutions – resorting to state intervention only as a last resort.

From the outset, Portugal's regime of 'unsupported familism' was characterised by limited public or subsidised services and an absence of policies supporting informal carers. Policies addressing care for older people began to emerge only in the late 1990s, under a weakly defamilialising orientation with little focus on caregivers' needs to balance paid work and caregiving responsibilities (Wall *et al.*, 2014). A recent latent profile analysis by van Damme *et al.* (2025), examining the extent to which care responsibilities are decoupled from the family and how familial dependencies are reinforced, identified Portugal in 2009 as a case of 'familism by default'. Like Italy, Portugal offers limited support for both informal and formal care (Eggers *et al.*, 2020). Nevertheless, the regime has slowly begun to shift, with gradual developments in formal services and growing support for informal carers.

Portugal's residual LTC regime is marked by low public spending, limited services, and meagre cash transfers, with low coverage rates across all forms of provision – residential care, home care, and financial support for dependents or informal carers. These services reach only a small fraction of those in need. The predominant role of informal family-provided care aligns with Portugal's low government expenditure on LTC, which stood at just 0.5% of GDP in 2019 (De Biase and Dougherty, 2023: 7). Coverage rates for health and social care services for people aged 65 and over remain very low, though they have been gradually increasing (Lopes, 2016).

In the public sector, LTC is mostly limited to continued healthcare services, while formal social care is largely provided by private, non-profit third sector organisations, known as Private Institutions of Social Solidarity (IPSS), many of which are faith-based (Ferreira, 2006; Lopes, 2016; Branco, 2022). These services are financed jointly by the state and user co-payments, through protocols negotiated with Social Security (Costa-Font *et al.*, 2012; Branco, 2017) and receive three-quarters of total long-term care spending (OECD, 2024).

The National Network of Long-Term Integrated Care, established in 2006 under the Ministries of Health and Social Solidarity, aimed less at creating new services and more at coordinating existing ones. It did not substantially alter the privatised logic of care provision: the state acts as a coordinator and funder, while service delivery remains largely delegated to private institutions – three-quarters non-profit and one-fifth for-profit – with public facilities accounting for only about 4 per cent (Lopes, 2016). Prior to 2019, there was only a modest expansion of home-based services and day-care centres. Additionally, a small but growing for-profit residential care sector, often weakly regulated, accounted for over 20 per cent of nursing homes and home-help services by 2020. In recent years, large corporations have increasingly targeted the high-income market for assisted living in urban centres like Lisbon and Porto.

The scarcity of formal services is compounded by limited time-related rights and inadequate cash-for-care benefits. Short-term leave is unpaid, and long-term leave is not available. As of 2017, Portugal had not implemented the EU recommendation for paid short-term leave at least equivalent to sick pay. Prior to the reforms of the Informal Carer Statute (2019) and the Social Benefit for Inclusion and Disability (2017), the only financial support available was a care allowance (dependency supplement) paid to pensioners aged 65 and older. While eligibility was universal, access was based on dependency level and then also means-tested from 2013 onwards. The benefit was so modest and access so restricted that it effectively functioned as a form of poverty-targeted social assistance.

As a result, families bear the majority of both the costs and labour of caregiving. Portugal had one of the highest rates of informal caregiving among EU-27 Member States in 2016, with 12.3 per cent of its population providing informal care compared to the EU-27 average of 10.3 per cent (European Commission, 2021b: 344). Moreover, the country has the largest share of intensive caregivers (defined as spending eleven hours or more per week on caring activities) and the greatest gender imbalance in Europe, while ranking second to last in the generosity of formal LTC provision (Baptista and Perista, 2018; Verbakel, 2018: 439–440). According to the latest data, in

2019 12 per cent of the resident population provided informal care to dependents, of which 80 per cent cared for family members, 42 per cent devoted more than ten hours per week to care, and two-thirds are women (Kalavrezou *et al.*, 2025). Researchers have valued the work of Portuguese informal carers at €4 billion annually, equivalent to approximately 2 per cent of Portugal's GDP in 2019 (Teixeira *et al.*, 2017).

Regarding the intersection of care with labour market and migration policies, higher than the European average employment rates have long imposed a double burden on Portuguese women. Many households rely on domestic workers to perform caregiving tasks under a variety of contractual arrangements. Although the number of female migrant care workers has increased in recent years, most caregivers remain native Portuguese women. This contrasts with the 'migrant-in-the-family' model common in Italy and, to a lesser extent, Spain and Greece (Wall and Nunes, 2010). Consequently, Portuguese women often struggle to balance labour market participation with elder care responsibilities. Their quality of life tends to be lower, due to long working hours, limited leisure time, and frequent neglect of their own health (Barbosa and Matos, 2014; Barbosa *et al.*, 2023).

Drivers of policies supporting informal carers: the role of social movements and political parties

The expansion of caregiver policy support is driven by several factors. First, demographic trends such as population ageing, longer life expectancy, and the rise in age-related illnesses, combined with severe formal care workforce shortages, have made informal caregiving a cost-effective alternative under rising LTC costs and economic pressures (Gori and Luppi, 2024). Second, EU and national policies increasingly emphasise labour market participation, especially among women and older workers, positioning informal care as a key element in work-life balance strategies (Kröger and Yeandle, 2013). Third, policies supporting informal care are compatible with the revealed cultural preferences and norms of care recipients and their relatives (Naldini *et al.*, 2016). Fourth, research on policy transfer has generally concluded that the success of diffusion depends on domestic conditions, such as actors, interests, ideas, and path dependencies (Theobald and Kern, 2011).

Finally, policy support for informal carers can also respond to demands from advocacy movements seeking recognition and assistance. Such groups engage with political actors and may be able, with varying success, to demand and shape government policy – the Carers UK movement and the Carers (Recognition and Services) Act of 1995 being exemplary of these dynamics (Larkin and Milne, 2014).

How to frame the relationship between social movements and political parties in the policy process? Parties and social movements perform complementing functions in the process of democratic representation by articulating citizens' demands, as well as to decision-making by aggregating preferences and sourcing information (Kitschelt, 2003). Politically oriented social movements voice demands unaddressed by parties and relate conflicts yet to be articulated in institutional politics (Hutter *et al.*, 2018) by representing constituencies hitherto mobilised or lacking formal representation (Tilly, 1984; Gamson, 1990). The informal carer social movement, in particular, fights for recognition – as a social group whose work has not been perceived as such and did not enjoy access to collective forms of representation – and for redistribution – that is, social policies valorising the work of caring to access labour rights and social protection entitlements (Fraser, 2009).

Once mobilised, their policy impact depends on whether institutions are receptive to societal demands and whether political allies and routine channels for movement-state interaction exist (Kriesi, 1995). Favourable public opinion also enhances their ability to influence policy (Burstein, 1999). Political elites are particularly responsive to protests that gain media attention, interpreting them as signals of urgent societal problems and electoral pressure from mobilised constituencies

(Uba, 2016). Political mediation theory further suggests that movements are more likely to succeed when forming alliances with sympathetic state actors, such as elected officials or bureaucrats, who perceive strategic value in supporting them (Amenta *et al.*, 2018).

Political parties can be crucial allies for social movements. When movements bring issue-specific conflicts into public debate framing them in politically resonant ways, they strengthen the position of supportive parties (Kriesi, 2015). Parties, especially ideologically aligned ones, may adopt movement causes for strategic or normative reasons, as is often the case with mainstream and radical left parties (Kriesi *et al.*, 1995). When in opposition, such parties may partner with movements to broaden or differentiate their political agenda. Piccio (2016) argues that the influence of movements is greater with ideologically aligned, vulnerable parties in need of electoral support and when party members are deeply involved in the movement.

In some historical contexts, the connection between social movements and political parties is more direct in that so-called ‘movement parties’ set up and lead social movements, using them as front organisations to recruit and mobilise members, as seen in the cases of the *Bloco de Esquerda* (Left Bloc) in Portugal or *Podemos* in Spain. These ties often strengthen following protest periods, such as those against austerity, and can extend into subsequent political cycles (Della Porta *et al.*, 2017). From 2015 to 2019, for example, Portuguese radical left parties entered for the first time a political agreement supporting the minority centre-left Socialist Party government. However, the compromises required by coalition governance may lead to a degree of de-radicalisation within radical left parties.

Data and methods

This paper examines the policy process that led to the adoption of a novel policy institution (Howlett and Cashore, 2014). In the tradition of social policy research, we conceptualise public policies as authoritative decisions that involve governmental choices regarding the selection of goals, instruments, operational settings, and the means to achieve them. Beyond technical implementation, public policies also serve to regulate and legitimise social actors, endorse or contest recognition claims, and make distributive decisions (Amenta and Young, 1999).

Our empirical investigation of this concrete policy case is based on extensive and diverse documentation. This includes news articles, electoral manifestos, draft legislation, parliamentary hearings, and a rich archive of political debates in parliament.

To evaluate the political impact of the caregivers’ social movement, we disaggregate the policy process into three analytical stages: (a) agenda setting, (b) legislative content, and (c) policy adoption (Amenta *et al.*, 2010: 291). At each stage, we apply a qualitative methodology that triangulates data from multiple sources. We compiled an original dataset comprising forty-nine documents: forty legislative bills and nine parliamentary debates covering the 2016–2019 legislative term (see Table 3, Appendix).

Across all parliamentary debates related to the adoption of the ICS from 2016 to 2019, we identified approximately 500 instances of political discourse voiced by thirty-three political actors. Each discourse instance was coded using a theoretically grounded framework of twenty-two primary categories. These categories were organised according to Le Bihan *et al.*’s (2019) functional classification of family care policy instruments, which includes: (i) compensation measures, e.g., cash transfers, social protection for carers, pension contributions, or tax relief; (ii) support measures for caregivers, such as information provision, counselling, training, and formal recognition of care work; and (iii) work-care reconciliation measures, including care leave entitlements, flexible working arrangements, and other time-based rights. Additionally, we introduced a category to capture normative ideals of care (Fine, 2015), distinguishing whether care was primarily framed as an expression of love or as a burden (see Table 5, Appendix).

We used MAXQDA software for the qualitative coding of political discourse. This software also allowed us to integrate qualitative coding with quantitative analysis, particularly to examine how

the frequency of specific discourse elements correlated with parties' ideological orientations (see Table 4, Appendix). Importantly, we did not code for the directionality of the discourse – whether statements were in favour of or against a given policy. Therefore, to enrich and contextualise our findings, we supplemented the coding with illustrative quotations that highlight key policy positions, ideological cleavages, and conceptions of care.

The informal caregiver statute: social movements and parties in the policy process

The political involvement of the IC movement developed in stages, beginning with mobilising for collective action, followed by raising public awareness to garner societal support, then engaging with political actors, and using petitions to present their demands to the national parliament.

In the first step, the movement coalesced into a cohesive collective in June 2016 for the event National Meeting of Informal Caregivers of Alzheimer's and Similar Diseases, organised with the political support of the radical left party Left Bloc (Bloco de Esquerda, BE) in connection with the European United Left/Nordic Green Left party. The IC movement issued a petition to parliament showcasing caregivers' policy demands, including the creation of a Statute of the Informal Carer. Drafted by a key partisan ally, José Soeiro (an IC movement activist and member of parliament for BE), the Petition formally entered parliament on October 2016. Framing caregiving as 'a heavy burden that can jeopardise the health and emotional well-being of the carer', it called for the recognition of caregivers, a raft of support measures for carers and a mild decoupling of the family from care work by the increase in formal services by national Network of Integrated Continued Long-Term Care (AR, 2016).

The media and political authorities were two key mediation channels used to politicise the issue and leverage public support. The national media followed closely the developments and amplified caregivers' voices and grievances, as reported by Soeiro (Soeiro and Araújo, 2020; Soeiro *et al.*, 2020) and key activists (Canha, 2020). For instance, the media group closely linked with the Catholic Church was an early ally.¹ The Catholic news radio echoed the key demand: 'informal carers want a subsidy', after airing an interview with Anabela Lima, one of the petitioners.² The daily paper of reference *Público* provides another example of a media ally repeatedly elevating caregivers' voices and demands.³

At the same time, the movement started to engage with members of political parties and made a powerful ally in the President of the Republic, whose endorsement of the creation of the Statute, and specifically caregiver support, lent an important political momentum, as reported by the daily paper *Público*.⁴ At the time the Petition reached the Committee on Labour and Social Security in 2017 the President described the informal carer's plight as a 'national cause' that unites 'all parties', a cause that 'the President has always defended and will continue to defend until it becomes a reality'.⁵

The political breakthrough came when, in response to the Petition entering parliament, parties first set up working group to elaborate a draft proposal of a Statute, completed by September 2017 (Canha, 2020). The Petition was met by a prompt response from BE and the Portuguese Communist Party (PCP), which submitted draft laws, while the right-wing conservatives CDS-PP (Christian Democrats) and the green left PAN (People, Animals and Nature) introduced resolutions.⁶ A second working group was formed to coordinate these initiatives and hold hearings with a broad set of social movement actors.⁷ In 2019, CDS-PP, the centre-right PSD (Social Democratic Party), and PAN also put forward draft laws.⁸ Unlike the other political parties, the incumbent centre-left Socialist Party (PS) did not submit a bill project; instead, the Socialist government submitted a draft law in February 2019, which did not create a specific Statute, relying instead on expanding individual support measures.⁹ Drawn-out negotiations eventually bore fruit with the creation of the Statute in the summer of 2019 (Law 100/2019).

The new law created a means-tested informal caregiver support allowance. Other proposals, such as updating the monetary value of existing subsidies, from the left, or introducing a contractual framework for family caregivers, from the right, were set aside. Additional provisions

included social protection measures, such as counting caregiving periods towards old-age pension calculations, and the possibility of accessing home support services for respite.¹⁰

According to the OECD the new law strikes a skewed balance between the need for a token of recognition to a large share of informal carers and the financial support for those providing most care (Rocard and Llena-Nozal, 2022). The fact that the law differentiates between two types of informal carer enshrines a new inequality. While the *principal carer*, a family member living in the same household as the care recipient for whom she provides care on a permanent basis, is eligible for the carer's allowance and for other types of support like respite care, the *non-principal carer*, a family member caring on a regular but non-permanent basis, is not eligible for a carer's allowance but can benefit from other types of support.

Table 2 allows us to assess in finer detail the impact of the social movement as a shaper of policy choices. As a general matter, the legislative end-product only partially complied with the breadth of the social movement's policy demands. Of the twenty-six proposed measures, only ten ended up in the Statute. Of these, only one was not supported by the governing party PS, which goes to show the incumbent party's decisive role in selecting which measures to adopt and their level of protection. As for cash transfers, the law opted for a less generous choice of care subsidy than the one aired by the movement, the same for increasing existing cash subsidies (against the broad opposition from left to right). Similarly, in the domain of social protection, the law ended up denying the more expansive choices voiced by the movement and radical left allies (e.g., the recognition of the time of care work as part of the contributory record towards pensions), only partially compensated by easing in the access to other social protection benefits. The third main area of disjunction between the demands of the movements and radical left parties and the final Statute is around labour market measures and work flexibility (here joined by right parties) towards the conciliation of care and salaried work. The PS government's argument was that the appropriate place to discuss such measures would be by tripartite social concertation, but the government never triggered that process.

From the IC movement's point of view, the law's main shortcomings were the lack of generosity of the care benefit, the access to it being limited to principal carers, the fact that no additional vacation days to the informal carer nor entitlement to days of absence from work (e.g. to accompany the cared-for person to a medical appointment) were provided, and the eligibility for the Statute being limited to family members only, thus excluding, for example, care provided by friends or neighbours (as reported by Perista, 2019).

A close reading of the policy debates in parliament over the period 2016 to 2019 shows that's the wide cross-party convergence for home-based care as the policy choice obscures variation in a set of dimensions associated with care.

Political parties diverge significantly in their underlying conceptions of care. One perspective, shared by centre-left and right-wing parties, views care primarily as a function of social reproduction within the family and as an expression of love. In contrast, radical left parties and most social movements conceive of care as a burden, advocating for optional familialism over the 'aging in place' model promoted by the former. Those holding the former view consider family-based care to be 'a more humane and better integrated alternative to institutionalisation', portraying informal carers as altruists performing 'an act of love from one person to another' (PSD, 2019). The latter's perspective emphasises the challenges faced by carers and those they support, including 'physical and psychological overload, exhaustion and even depression', along with a 'considerable increase in health costs' (PCP, 2018a).

Accordingly, advocates of home-based care support public policies that enable 'the sick person to stay at home' (CDS-PP, 2017), while also calling for improvements to the 'conditions and well-being of informal carers' (PS) and for 'support for informal carers without jeopardising their health' (CDS-PP, 2018b). Conversely, others argue that caring 'ought to be a choice', not an imposed obligation. While acknowledging that care can be 'a demonstration of generosity and attention to others', they stress the significant toll it can take (BE, 2018).

Table 2. Proposals presented in the policy process by the social movement of informal carers and parties

				Parties						ICS Law 100/2019	
				Social Movement Petition	GOV	Right Parties		Left Parties			
						PS	PSD	CDS	BE		PCP
Measures											
Compensation	Cash-transfers	Increase in existing subsidies	✓*		+	+	+	+	—		
		Allocation of survivor's pension	✓								
		Allocation of death grant	✓								
		Care allowance for IC	✓*	—	—	—	+	+	—	—	
	Social protection	Work of care recognised for social contribution records	✓		—	—	=	—	=		
		Access to early retirement	✓*		=	=			=		
		Social protection access criteria	✓	+	+	+	+			+	
		Tax reliefs	✓		+	=			+		
		Housing aid							+		
		Transport aid			+	+	+	+	+		
		Professionalisation of carers			+	+					
	Supportive	Information	✓	=	=	=	=	=	=	=	
		Counseling	✓	=	=	=	=	=	=	=	
		Training	✓	=	=	=	=	=	=	=	
Humanisation of services				+	+						
Human resources for caring			+	+	+	+	+	+			
Public institutions		Carer's respite	✓*	=	=	+	+	=	=	+	
		Expansion of formal services	✓		—	—	=	=	=		
		Priority service	✓		+				=		
		Creation of a public network of IC	✓*								
		Acknowledgment/creation of the ICS	✓	—	=	=	=		=	=	
		Leaves from caregiving	✓*			+	+		—		
Home support		Reinforcement of home support	✓*		+	+	=	=			
	Third-party support for carers	✓									
Conciliation	Care leaves from employment	✓*		+	+	+	+	—	=		
	Work flexibility	Shorter working hours	✓		—	—	=	—	=		
		Telework			+	+			=	+	
		Continuous work			+	+			+		
		Part-time	✓*			=	=		=		

(Continued)

Table 2. (Continued)

Measures	Social Movement Petition	Parties						ICS Law 100/2019
		GOV PS	Right Parties		Left Parties			
			PSD	CDS	BE	PCP	PAN	
Extension of licences	✓*	—	+	+	+	+		
Flexible working hours	✓*		=	+		=	=	
Fiscalisation of LM legislation	✓*					=		
Working hours adapted to IC needs	✓*					=		
Student-worker status	✓*		=	=		=	=	
Tax reliefs for IC friendly firms	✓*							
Early education and child support					+	+	+	

Source: own elaboration using MAXQDA.

Primary sources: see endnote 12.

*: Although not included in the original Petition, these demands were made by at least one of the following associations in their written contributions: Associação Cuidadores – melhorar a vida de quem cuida; European Working Group of People with Dementia; Acreditar; O céu é o limite; Plataforma Saúde em Diálogo; Associação Cuidadores Portugal; Observatório de deficiência e direitos humanos; APREI; Familiarmente; MODERP; Movimento Filhos Sem Voz; and Federação Portuguesa para a deficiência Mental.

Key: — : less generous than Petition; = : similar to Petition; + : more generous than Petition.

Another point of divergence concerns public investment and the financial implications of different care models. Supporters of family care often frame it as a cost-saving strategy vital for maintaining fiscal sustainability. They argue, for example, that ‘de-institutionalisation brings savings in public expenditure’ (PSD, 2017), and that the government must balance the needs of care recipients with the imperative to ‘manage public funds and services effectively’ (CDS-PP, 2018a).

In contrast, proponents of defamilialising care argue that meeting the needs of both informal carers and care recipients requires greater public investment. They call for increased funding for formal care (PCP) and the expansion of both the National Network of Integrated Care and home-support services (BE). However, these proposals failed to secure a parliamentary majority – largely due to opposition from the governing centre-left PS. As a result, only a more limited measure, the ICS, was enacted.

Figure 1 shows the issue salience (relative frequency) of policy instruments voiced in political debates, grouped in accordance with partisan ideological orientation between three political groupings: the centre-left Socialist Party and government in office, the right-wing opposition parties (PSD and CDS-PP), and the (radical) left parties on whose support the minority government had been relying on since 2015 (BE, PCP, and PAN), and ordered according to a declining scale of total average salience.

Overall, we find the major concern to be with compensation and conciliation measures. Political actors focused on compensating unpaid care work through cash transfers and social protection access, as well as addressing quality care that ensures good practices in home-based care, again and again underlined the importance of information, training, and counselling. Less salience is given to the investment in public institutions and human resources for care, which illustrates the lack of support for the public formal care reform path.

However, there is variation in the salience of each item between the centre-left, the left-wing, and the right-wing parties. The deep preference of left radical parties is for structural change in the care regime towards formal care. However, faced with a majoritarian opposition, they turned their efforts into improving the lives of caregivers, through cash transfers, employment and work

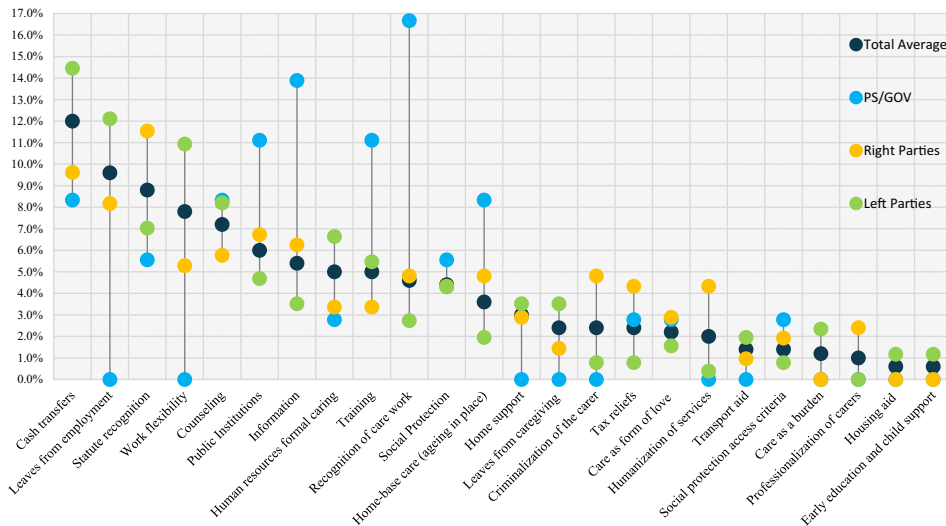


Figure 1. Issue salience of policy instruments by programmatic orientation (2016–2019).
Source: own elaboration using MAXQDA.

flexibility, and care leaves from work. At the end of the day, once de familiarisation via public-supported formal care was implausible, left parties insisted on creating conditions allowing carers to reconcile their professional, family, and social lives with the care provision (PCP, 2018a, 2018b).

Government and right-wing parties sought to strengthen home-based care focusing on ‘the invaluable social role of informal carers’ (PSD, 2017) and the ‘unquestionable social value’ of carers’ work (CDS-PP, 2017). The government insisted that the proper place to discuss labour market issues would be social concertation, and so largely refrained from such topics. Both right-wing parties and the executive pursued a clear strategy of aging in place, viewing caring as the scope and responsibility of carers, as a labour of love. Not surprisingly, they insisted on counselling and information, but right-wing parties especially stressed the recognition offered by the Statute itself as even more important. These parties have long claimed to recognise the role of informal caregivers, but only as another staple of the family-based care model. This is in keeping with the greater salience given to cash subsidies than to institutions providing care outside of the family (public institutions, professional resources for caring). The emphasis on skilling care workers via information, training, and counselling points in the same direction.

By contrast, the preferences of social movement actors are aligned with radical left parties. The National Association of Informal Caregivers described the work of caring as a heavy burden put upon family members, and demanded public care services to prevent carers from developing exhaustion and burnout (Associação Pais em Rede, 2018a); as well as expanding the territorial coverage of care institutions (Observatório da Deficiência e Direitos Humanos, 2018a); and care-related services that guarantee the effective coverage of formal care (APRe, 2018a), because ‘informal carers are not professional formal carers, so the informal carer must have support from formal structures, even if there is an ICS’, said Liliana Gonçalves, first signatory of the original Petition. The petitioners were concerned that ‘carers are being given responsibilities that are not theirs’ and the risk of skill deficits impacting the quality of the care provided. If care is to be provided at home, then both professional assistance and training were deemed essential.

Concluding remarks

This article examines the political dynamics behind the adoption of the Informal Caregiver Statute in 2019, with a focus on the politically mediated influence of the carers’ movement on

the policymaking process. The movement represented carers' interests, articulated clear policy demands, and found allies across the political spectrum, from the president of the Republic to political parties. It helped set the agenda both in Parliament and public discourse, partially influenced the policy design of the final Statute, and successfully politicised the issue by bringing the plight of informal carers into the political arena, challenging the long-standing invisibility imposed by Portugal's familistic care regime, as the literature has pointed out (Soeiro and Araújo, 2020; Canha, 2020; Gil, 2024).

However, the final ICS is far from a direct translation of the movement's demands as presented in its Petition and parliamentary hearings. Despite cross-party unanimity, the ICS reflects a narrow compromise aimed at modestly improving carers' conditions. While it was prompted by carers' activism and shepherded through Parliament by a few partisan allies, the proposal faced initial resistance from the minority centre-left government. Throughout the legislative process, political parties, especially the centre-left Socialist party in office, embedded their own preferences into the policy, sometimes aligning with the movement's goals, other times diverging.

Indeed, our analysis revealed the underlying partisan divisions beneath the surface of consensus. The right parties and the centre-left government supported in-place, family-based care – partly to enhance quality and partly for cost-saving. In contrast, radical left parties and movement actors advocated for public investment in formal care services, citing goals of universal access, reduced dependency on families, and addressing regional disparities. For them, care was not a 'labour of love' but a burden that individuals should be able to choose whether to bear.

The Portuguese reform is an instance of a wider trend. Indeed, from 2017 to 2021, many EU Member States improved conditions for informal carers. Key measures include introducing carer's allowances, leave entitlements, training, psychological support, and respite care. Countries introducing or enhancing carer's allowances include France, Slovakia, the Czech Republic, and Poland. Carer's leave and work-life balance policies were expanded in Belgium, Austria, Croatia, and Spain. Training and respite services have been developed in Bulgaria, Finland, France, Ireland, Lithuania, Luxembourg, and Poland (European Commission, 2021a: 88–89). This trend towards formally integrating informal carers in the publicly supported provision under a variety of guises, far from furthering de-familiarisation processes, has 'instead blurred the boundaries between formal and informal care resulting in a *de facto* further familiarisation of care', as asserted by Simmons *et al.* (2024: 212).

Important as it is, the Statute may foreclose alternative paths for care reform in Portugal. For instance, if the explicit goal would have been to *decouple care from the family*, or make it into an *available option*, policymakers could in theory have pursued a market-based model, treating care as a commodity provided by the for-profit sector, or could have pushed for a universal, tax-funded public care service, akin to the 'National Care Service' proposed in the Left Bloc's 2024 election manifesto (BE, 2024). Instead, the ICS entrenched a hybrid model of supported familism, without fundamentally reducing the system's reliance on subsidised third-sector organisations for formal care provision.

Adjustments to the Statute are ongoing, driven by continued mobilisation. The National Association of Informal Carers submitted in a 2022 a 'citizens' legislative initiative' to Parliament demanding changes to the ICS, including broader eligibility, elimination of means-testing for subsidies, improved respite rights, and more flexible work-care reconciliation policies (Gil, 2024: 111). The government has partially addressed some of these demands, by broadening eligibility, simplifying administrative procedures and improving support measures for carers as regards the right to enjoy respite from caring work (Decree-Law 86/2024). Could such incremental changes move the care regime towards the *optional familism model*, one in which care is a choice, rather than an obligation, of family members? While that may be optimistic – though not implausible, as shown by the French case (Le Bihan, 2023) – one conclusion is clear: sustainable care systems are unlikely without robust public investment in the provision of formal care.

Supplementary material. To view supplementary material for this article, please visit <https://doi.org/10.1017/S1474746425100882>

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Notes

1 See <https://rr.pt/artigo/trabalho-sem-fronteiras/2016/07/05/por-amor-a-vida-dos-cuidadores-de-alzheimer-e-uma-luta/57880/>, accessed 28.2.2025.

2 See https://rr.pt/noticia/108303/cuidadores-informais-querem-subsidio-damos-a-ganhar-ao-estado-muito-dinheiro?utm_medium=rss, accessed 28.5.2025.

3 See <https://www.publico.pt/2017/04/02/sociedade/noticia/quem-sao-os-cuidadores-informais-em-portugal-1766944>, and <https://www.publico.pt/2016/04/07/sociedade/noticia/governo-e-cds-de-acordo-e-preciso-apoiar-cuidadores-de-idosos-em-casa-1728387>, accessed 28.2.2025.

4 See “Marcelo considera urgente estatuto legal para cuidadores de doentes de Alzheimer. <https://www.publico.pt/2017/09/21/sociedade/noticia/marcelo-considera-urgenteestatuto-legal-para-cuidadores-de-doentes-de-alzheimer-1786208>; “Marcelo diz que país não pode continuar a adiar estatuto do cuidador”. <https://www.publico.pt/2018/11/05/sociedade/noticia/marcelo-pais-nao-continuar-adiarestatuto-cuidador-1849905>; “Marcelo sublinha importância da efetiva aplicação do Estatuto do Cuidador Informal”. <https://www.publico.pt/2019/11/05/politica/noticia/marcelo-sublinha-importanciaefectiva-aplicacao-estatuto-cuidador-informal-1892506>, accessed 19.6.2025.

5 The IC movement commissioned Merck for a national survey during the year of the pandemic, which painted a dire picture of a life of hardship due to the burden of caring. The results, presented in a public conference by the president of the Republic, were widely publicised in the media. See <https://envelhecer.pt/merck-movimento-cuidar-dos-cuidadores-informais/>, accessed 28.2.2025.

6 BE (2018); PCP (2018a); CDS-PP (2018a); PAN (2018).

7 AR (2018a; 2018b; 2019). A cleavage emerged within the social movement over the course of multiple parliamentary hearings between those embracing caregiving responsibilities (such as Plataforma Saúde em diálogo; Associação Filhos sem Voz; O céu é o limite; Grupo ECI JÁ!) and those favouring the increase in formal public services (such as APRe; Acreditar; Associação pais em rede; Familiarmente; Associação Cuidadores; Observatório da deficiência e direitos humanos). As we shall see below, a similar cleavage would shape the debate between centrist/right parties and radical left parties.

8 CDS-PP (2019a); PSD (2019); PAN (2019).

9 GOV (2019).

10 BE (2017, 2018, 2019); CDS-PP (2017, 2018a, 2018b; 2019a, 2019b); GOV (2019); PAN (2018, 2019); PCP (2017, 2018a, 2018b); and PSD (2017, 2019).

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