ORIGINAL INVESTIGATION

Informal support in Portugal by individuals aged 50+

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Abstract In Portugal, individuals aged 50+ have an important role in the provision of co-residential care. This study aimed to rank Portugal relative to 15 European countries with regard to the prevalence of co-residential care (daily or almost daily personal care), and extra-residential help/care (household help and/or personal care) provided by individuals aged 50+, and determine the factors associated with the provision of these types of support in the Portuguese context. The study used data from the SHARE wave 4 project (2010-2011) and was based on an analysis of variance and logistic regression models. Portugal differs from other European countries, as it has the highest rate of coresidential care (12.4 %) and the lowest rate of provision of extra-residential help/care (10.8 %). It is concluded that the quality of life (QoL) of Portuguese co-residential carers is lower than the QoL of non-carers, but extra-residential help/ care provided once a month or less has a positive impact on the QoL of the providers. Co-residential care and the provision of frequent extra-residential help/care (daily or weekly) were associated with a higher number of depressive symptoms. The results further showed that, in Portugal, coresidential carers and extra-residential helpers/carers have different socio-demographic, economic and health characteristics. This study demonstrates that it is important for scientific research to differentiate the type and frequency of informal support, since this can help us design policies to

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meet the specific needs of the various types of informal carers aged 50+.

Keywords Co-residential carers · Extra-residential helpers/carers · Carers aged 50+ · Quality of life · Portugal

Introduction

Recent official statistics show that there is an increasing tendency for older people to be involved in providing informal support to others (Pickard and King 2012; Hosseinpoor et al. 2013). Among other factors contributing to this situation are the reduction in families' size and the greater number of women in the workplace. Moreover, increased life expectancy and overall improvements in health allow older people to undertake socially productive functions after retirement, namely the role of carers (Rösler-Schidlack et al. 2011). In this way, they respond to the growing need for informal support, brought about by a longer life span and policies of de-institutionalization of older people (OECD 2013; Hosseinpoor et al. 2013).

In Southern European countries, individuals aged 50+ have poorer health than their counterparts in Northern and Western countries (Eriksen et al. 2013), which tends to mean an increased need for care in the former countries. Recent studies show that, in Southern Europe, the needs of older people are addressed essentially by informal networks, whilst in Northern countries, they tend to be met by formal providers (Lyberaki et al. 2013). Scientific studies also show that informal support has different characteristics across European countries. In the South, informal support mainly involves support for activities of daily living (ADL) (informal care) and is characterized by being very frequent (daily frequency), whilst in Northern

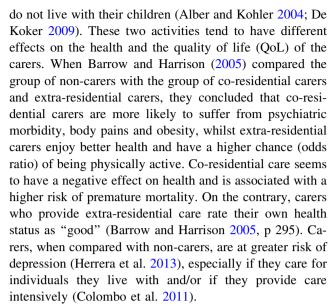


countries, informal support covers instrumental activities of daily living (IADL) (informal help) and happens in a more sporadic way (Colombo et al. 2011; OECD 2013). Informal support also tends to differ in terms of location. Co-residential care is more frequent in Southern countries, whilst extra-residential help/care is more common in Northern countries (Hank 2011; Rodrigues et al. 2012). Factors such as living arrangements—higher levels of coresidence in Southern countries and a higher number of people living alone in Northern countries—and the lack of formal care services at home in Southern countries can help one explain the differences.

The structures of opportunity (welfare states) and family culture have a strong impact on older people's degree of involvement in socially productive activities, either encouraging or discouraging this involvement (Igel et al. 2009; Brandt et al. 2009). The high proportion of individuals who help others, in countries with strong welfare states, seems to confirm the thesis that the existence of a broad range of formal services tends to encourage informal help from the family, to the detriment of informal care (Motel-Klingebiel et al. 2005). In Northern countries, which have strong welfare states, the existence of a wide range of social services tends to decrease the intensity of informal support from family members, freeing them from heavier jobs (Brandt et al. 2009). The formal carers carry out essential tasks, which are more demanding and intensive, whilst family members tend to carry out lighter tasks (Brandt et al. 2009). In countries where the welfare state is weak (Southern European countries), the family tends to be the main entity responsible for the care of the dependent individuals. In these countries, called family-orientated, the family group is self-sufficient, and the State does not provide relevant support to the families and to the individuals in need (Brandt et al. 2009). In Southern European countries, the State guarantees the fulfilment of family responsibilities 'by force', or rather, through the lack of an alternative (Daatland 2001, p 19) since the cost of care homes and professional services at home are high (Callegaro and Pasini 2008) and no real improvement in social policies has been made (Sarasa and Mestres 2005).

Co-residential care versus extra-residential help/care

Scientific literature shows evidence of the differences between co-residential care and extra-residential help/care (Barrow and Harrison 2005; De Koker 2009). Co-residential care has a more intensive nature, implying more hours of work and more emotionally exhausting tasks. This kind of care is normally provided by individuals aged 60 or over and who have health problems of their own (Glendinning et al. 2009; Alber and Kohler 2004; De Koker 2009), whilst extra-residential help/care is mainly carried out by women aged 60 and under, and married adults who



The impact of giving informal support on the QoL of older carers is unclear. Various studies have suggested that care provision by individuals aged 50+ significantly reduces the QoL of the carers (Netuveli et al. 2006; Rösler-Schidlack et al. 2011). However, Ekwall et al. (2005) concluded that older informal carers aged 75 or older have a greater QoL. Providing extra-residential help seems to have a positive effect on older people. Wahrendorf et al. (2008) stated that individuals involved in this type of activity show greater QoL.

The Portuguese context

According to the latest statistics, the number of individuals aged 65+ in the Portuguese population increased from 16.4 to 19.4 % between 2001 and 2012 (INE 2012, 2013). This is the outcome of an increase in the average life span, low fertility rate and migration flows (António 2013). In Portugal, life expectancy has risen from 66.7 years in 1970 to 80.8 years in 2011 (OECD 2013), but individuals aged 65 and over rank last in reporting good health and healthy life years (OECD 2013). Furthermore, Portugal has the second lowest fertility rate in Europe (European Commission 2012; INE 2013). Due to the economic crisis, unemployment has risen from 7.6 to 16.3 % between 2008 and 2013 (INE/PORDATA n.a.), and there was a significant increase in emigration whilst immigration fell (INE 2013). In the last decade (between 2001 and 2012, more exactly), the old-age dependency ratio has risen from 102 to 131 (INE 2012, 2013), pushing the Portuguese Government to adopt new measures to ensure sustainable public finances, for example, the increase in retirement age, cuts to pensions and a rise in users' health charges.

The Portuguese demographic situation contributes to a reduction in the number of persons available to provide



informal support, whilst the socio-economic context has hampered older people's purchasing power. The majority of them cannot afford to pay for formal care, which is nevertheless insufficient in view of the population's needs (Portugal 2008). Formal care provided at home merely responds to basic necessities, such as food and hygiene, but does not help in solving problems of a more multidimensional nature (Carvalho 2012). Furthermore, the link between formal and informal care is weak (Santana et al. 2007), in spite of the existing legislation pointing to their integration. Portuguese informal carers are overburdened with instrumental tasks, which limit their social inclusion and participation, confining them to the household (Carvalho 2012).

Despite the above described situation, the Portuguese government does not legally recognize the role of informal carers, relying instead on the 'family's obligation to care for its ascendants and descendants, based on its affection and the central role of the family' (Portugal, 2007, p 43).

Bearing in mind the characteristics of the Portuguese context, we can draw the hypotheses that the prevalence of co-residential care in Portugal is high, compared with the majority of other European countries, and that co-residential carers aged 50+ have less QoL.

Methods

This study uses data from the Survey of Health, Ageing and Retirement in Europe (SHARE). SHARE is a multidisciplinary and cross-national panel database of micro data on health, socio-economic status and social and family networks from 20 European countries (+Israel) aged 50+.

The prevalence of co-residential care (daily or almost daily personal care) and extra-residential help/care (household help and/or personal care) by individuals aged 50+ in the 16 participating countries, in the 4th wave of SHARE (N=57,262), was calculated. Next, the analysis was confined to Portugal, by comparing the groups of co-residential carers (N=171), extra-residential helpers/carers (N=204) and non-carers (N=1,617), using an analysis of variance (Anova Unifactorial) and a test of association (Chi Square). Finally, the determining factors in the type of support in Portugal were studied, using the non-carers as a reference group in multinomial logistic regressions. Socio-demographic, economic, health (physical and mental) characteristics of the social network and QoL were all considered determining factors in logistic models.

Measures

In wave 4 (2010–2011), SHARE data have some limitations for this study. In extra-residential support, it is not possible to distinguish between care (personal care) and

help (practical household help). So in this analysis, we cannot specify the type of extra-residential support provided. In this sense, three groups of support were defined as dependent variables on multinomial logistic regression. The co-residential carers (1) are all the individuals who responded positively to the question 'Is there someone living in this household whom you have helped regularly during the last twelve months with personal care, such as washing, getting out of bed, or getting dressed'? The extraresidential helpers/carers (2) are those individuals who responded positively to the question 'In the last twelve months, have you personally given personal care or practical household help to a family member living outside your household, to a friend or to a neighbour'? The individuals who responded negatively to the two questions were categorized as non-carers (3). The individuals who simultaneously provided co-residential care and extra-residential help/care are a small group (N = 30), and they were therefore excluded from the analysis.

From a review of the literature, four groups of independent variables were adopted:

- Socio-demographic and economic variables Age; Gender; Marital Status (with partner/companion and other situation); Household size; Education (categorized in accordance with ISCED 97: with no schooling or preprimary = level 0; 1st and 2nd cycles = level 1; 3rd cycle = level 2; secondary = level 3; post-secondary = level 4, degree, master's or doctorate = level 5); Status of employment (Retired, Employed, Unemployed and Other situation); and Income (thinc variable): Low, Intermediate and High (income tertiles).
- Health variables Number of limitations with ADL; Physical activity: Yes/No (the presence/absence of moderate or intense physical activity); Memory assessed by an immediate register and a later recall of a list of ten words (the points awarded for immediate memory and later memory, 0-20 points, were added to one another, and a new variable 'memory' constructed, in which higher points are associated with better memory); Depressive symptoms, assessed on the EURO-D scale with 12 items: feelings of depression, pessimism, wishing death, guilt, irrationality, tearfulness, fatigue, sleeping troubles, loss of interest, loss of appetite, reduction in concentration, and loss of enjoyment over the previous month (Prince et al. 1999), with three or less depressive symptoms categorized as the absence of clinically significant depression and four or more depressive symptoms categorized as clinically significant depression (Dewey and Prince 2005, p 109).
- Social network variables Number of persons in the social network considered emotionally close or very close; and Number of social activities.



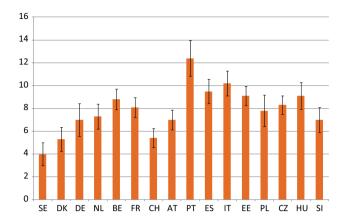


Fig. 1 Proportions of informal co-residential carers in the 50+ population. *Source* SHARE Wave 4 release 1; weighted data; N = 3,810 (unweighted)

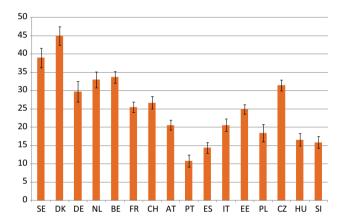


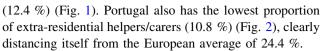
Fig. 2 Proportions of informal extra-residential helpers/carers in the 50+ population. Source SHARE Wave 4 release 1; weighted data; N=10353 (unweighted). Notes Whiskers represent confidence intervals (CI); Countries: SE Sweden, DK Denmark; DE Germany, NL Netherlands, BE Belgium, FR France, CH Switzerland, AT Austria, PT Portugal, ES Spain, IT Italy, EE Estonia, PL Poland, CZ Czech, HU Hungary and SI Slovenia

QoL, assessed by the CASP-12 scale, the short version of CASP-19 (Hyde et al. 2003), which comprises four dimensions: Control, Autonomy, Self-realization and Pleasure. The total number of points on the CASP-12 scale varies between 12 and 48 points, with a greater QoL corresponding to higher values.

Pearsońs correlation analysis was performed, and no strong relationships were detected between the measures.

Results

According to SHARE data, Portugal is the European country with the highest proportion of co-residential carers



Co-residential carers were those who experienced less OoL (29.97 points compared to 32.16 for non-carers and 33.64 for extra-residential helpers/carers) and were the oldest (67 years old, on average, compared to 66 years old for non-carers and 62 years old for extra-residential helpers/carers) (Table 1). Most individuals from each group had a partner/companion, especially in the group of coresidential carers (90 % with a partner/companion). The female gender was better represented in the group of extraresidential helpers/carers (70 % women), whilst co-residential carers were those with the least relative number of women (52.6 %). The extra-residential helpers/carers were the group with the highest level of education (average level of schooling = 2.8, compared to 2.1 for the co-residential carers and 2.3 for the non-carers) and the highest income (50 % belonged to the group with the highest income compared to 29.8 % in the co-residential carers group and 35.6 % in the group of non-carers). The group of co-residential carers had the highest proportion of retired people (67.3 %). In terms of health, the group of extra-residential helpers/carers had the highest levels of memory (8.9 points, on average), higher levels of physical activity (86.7 % of active individuals) and the least number of limitations in their activities of daily living (0.25 limitations, on average). The group of co-residential carers had the highest proportion of individuals with four or more depressive symptoms (56.7 % of the total number of individuals). Regarding the social network, the group of extra-residential helpers/carers had the highest number of close or very close individuals (2.67 persons), and social activities (2.15 activities), and the group of co-residential carers had the largest household sizes (2.87 individuals).

The socio-demographic and economic variables—health, social network and QoL explain 16 % of the variance in the provision of co-residential care and extra-residential help/care of Portuguese individuals aged 50+(Table 2).

Compared with the non-carer group, co-residential carers were mainly individuals with a partner/companion, retired, with greater limitations in their ADL, more depressed despite being more physically active and having larger households. Conversely, the extra-residential helpers/carers were predominately women, retired, individuals without a partner/companion and younger, with more emotionally close networks, with a greater number of social activities, more depressed, more physically active and with higher incomes.

The analysis revealed not only that co-residential care was associated with less QoL, but also that extra-residential help/care on a monthly or less frequent basis was



Table 1 Descriptive statistics for all variables by type of support

	Extra-residential helpers/carers $(N = 204)$	Co-residential carers $(N = 171)$	Non-carers $(N = 1,617)$	p value	X^2/F
Age, mean (SD)	62 (8.490)	67 (10.220)	66 (9.541)	< 0.001	14924,000
Gender	_			0.009	9.437
Female (%)	65.7	52.6	54.8	_	_
Male (%)	34.3	47.4	45.2	_	-
Marital status	-			< 0.001	20.389
With partner/companion (%)	71.1	90.1	79	_	-
Other situation (%)	28.9	9.9	21	_	-
Education (ISCED-97) , mean (SD)	2.8 (1.875)	2.1 (1.773)	2.3 (1.841)	< 0.001	7.683
Current job situation	-	_	_	0.001	22.21
Retired (%)	51.2	67.3	56	_	-
Employed (%)	30.5	15.8	22.6	_	_
Unemployed (%)	8.9	4.1	6	_	-
Other situation (%)	9.4	12.8	15.4	_	-
Income	_	-	_	< 0.001	19.837
Lower or intermediate (%)	50	70.2	64.4	_	-
High (%)	50	29.8	35.6	_	-
Memory, mean (SD)	8.9 (3.562)	6.86 (3.618)	7.39 (3.449)	< 0.001	19.293
Depression (Euro-D)	_	_	-	< 0.001	22.257
≤3 Depressive symptoms	59.3	43.3	61.8	_	-
≥4 Depressive symptoms	40.7	56.7	38.2	_	-
ADL Limitations, mean (SD)	0.25 (0.687)	0.85 (1.574)	0.38 (1.102)	< 0.001	16.397
Physical activity	_	-	_	< 0.001	16.715
yes (%)	86.7	73.7	73.6	_	-
No (%)	13.3	26.3	26.4	_	-
Number of social activities, mean (SD)	2.15 (1.789)	1.22 (1.357)	1.19 (1.398)	< 0.001	40.529
Very and extremely close members of social network, mean (SD)	2.67 (1.789)	2.41 (1.460)	2.13 (1.423)	<0.001	14.749
Household size, mean (SD)	2.44 (1.154)	2.87 (1.268)	2.42 (1.128)	< 0.001	12.123
CASP-12 (QoL), mean (SD)	33.6 4(5.521)	29.97 (5.568)	32.16 (5.568)	< 0.001	23.45

Source SHARE Wave 4 release 1; unweighted data; $X^2 = \text{Chi}$ Squared test; F = One-way ANOVA

associated with a higher QoL (Table 3). In contrast, individuals who provided weekly or daily extra-residential help/care were at a greater risk of suffering from four or more depressive symptoms (Table 3).

Discussion

Of the 16 countries analysed, Portugal has the highest proportion of co-residential carers aged 50+ (12.4 %) and the lowest proportion of extra-residential helpers/carers aged 50+ (10.8 %). This result confirms our first hypothesis of a high prevalence of co-residential care in Portugal.

This situation is paralleled to some extent in other Southern European countries, where caregiving is also seen as a family responsibility (Igel et al. 2009; Lyberaki et al. 2013). The macro-economic circumstances, with particular emphasis on the economic downturn and the lack of formal support structures for older citizens, on the one hand, and the difficult socio-economic circumstances of a significant number of the population, on the other hand, favour coresidential over extra-residential care (Sarasa and Mestres 2005; Isengard and Szydlik 2012). The smaller proportion of extra-residential helpers/carers has also been explained by different interpretations of the notion of "help" in the various countries. In Northern European countries, the



Table 2 Multinomial logistic regression (dependent variable = type of carer)

	Extra-residential helpers/carers (Ref. Non-carers)	Co-residential carers (Ref. Non-carers)
Age	0.956 (0.931-0.981)**	1.011 (0.986–1.036)
Gender	1.602 (1.128–2.275)**	1.003 (0.685–1.469)
Female	_	_
Male (ref.)	_	_
Marital status	_	_
With partner/companion	0.449 (0.302-0.669)***	2.238 (1.267-3.953)**
Other situation (Ref.)	_	_
Education (ISCED-97)	1.007 (0.917–1.106)	0.986 (0.909-0.985)
Current job situation	_	_
Retired	1.521 (0.953–2.428)+	$1.686\ (0.958-2.465)+$
Employed (Ref.)	_	_
Unemployed	1.376 (0.733–2.550)	0.727 (0.281-1.882)
Other situation	0.782 (0.425–1.439)	0.993 (0.505-1.954)
Income	_	_
Lower or intermediate (Ref.)	_	_
High	1.430 (1.022–2.001)*	0.847 (0.578-1.243)
Memory	1.043 (0.989–1.099)	0.992 (0.937-1.050)
Depression (Euro-D)	_	_
≤3 Depressive symptoms (Ref.)	_	_
≥4 Depressive symptoms	1.488 (1.035–2.139)*	1.487 (1.004-2.204)*
ADL Limitations	1.136 (0.923–1.398)	1.260 (1.087-1.460)**
Physical activity	_	_
yes	1.576 (0.971–2.558)+1	499 (0.953-2.357)+
No (Ref.)	_	_
Number of social activities	1.246 (1.126–1.379)***	1.070 (0.934–1.226)
Very and extremely close members of social network	1.152 (1.034–1.282)**	1.081 (0.958–0.1.221)
Household size	1.098 (0.944–1.278)	1.352 (1.178–1.551)***
CASP-12 (QoL)	1.035 (0.998–1.074)+	0.946 (0.909-0.985)**
Nagelkerke $R^2 = 0.163, p < 0.001$	_	_

Source SHARE Wave 4 release 1; unweighted data; N = 1,824 (194 Extra-residential helpers/ carers; 158 Co-residential carers; 1,443 Non-carers) Standardized odds ratios (confidence intervals 95 % in parentheses) + <0.10, * <0.05,** <0.01,***

< 0.001

 Table 3
 Multinomial logistic regression (dependent variable = frequency of Extra-residential help/care)

	Almost every day (Ref. Non-carers)	Almost every week (Ref. Non-carers)	Almost every month or less often (Ref. Non-carers)
Depression (Euro-D) (Ref. ≥4)	2.01 (1.09-3.70)*	2.00 (1.08–3.71)*	0.99 (0.53–1.69)
ADL Limitations	1.07 (0.73–1.58)	1.08 (0.72–1.62)	1.24 (0.94–1.63)
CASP-12 (QoL)	0.99 (0.94–1.06)	1.02 (0.96–1.09)	1.08 (1.02–1.14)**
Nagelkerke $R^2 = 0.156, p < 0.001$	_	_	-

Source SHARE Wave 4 release 1; unweighted data; N = 1637(1,443 Non-carers; 60 almost every day; 58 almost every week; 76 almost every month or less often). Adjusted for Age; Gender; Marital status; Current job situation; Income; Education; Memory; Physical activity; Social activities; Very and extremely close members; Household size. Standardized odds ratios (confidence intervals 95 % in parentheses)

+ <0.10, * <0.05,** <0.01,*** <0.001

significance attributed to the notion of informal help appears to be especially associated with emotional and affectionate dimensions (Ogg and Renaut 2006), whilst in the Southern countries, it has a more instrumental connotation and is therefore more restrictive. In this analysis, we

see that, despite similarities between Portugal and their counterparts of Southern European countries, Portugal has less extra-residential helpers/carers aged 50+ than Italy and Spain (Fig. 2). In relation to co-residential carers, Portugal and Italy have higher proportions and Portugal



differs from Spain the country with the lowest proportion in Southern countries (Fig. 1).

Co-residential carers and extra residential helpers/carers show different socio-demographic and economic characteristics. The latter are mainly women, as confirmed by De Koker (2009), and are younger individuals, as highlighted in several other studies (Alber and Kohler 2004, p 64; Burr et al. 2007; Glendinning et al. 2009). Despite being younger, the individuals who provide extra-residential help/care were less likely to be married than co-residential carers. Co-residential care, as well as extra-residential help/ care, is fundamentally carried out by retired individuals. This result is corroborated, in part, by the conclusions of other studies that point to the fact that individuals who give co-residential care and intensive care are less likely to be employed (Colombo et al. 2011; Glendinning et al. 2009), given the difficulty of combining caregiving with pursuing a professional activity. However, the same studies conclude that, in contrast to the results obtained for Portugal, the extra-residential helpers/carers tend to be individuals of working age who are employed or unemployed. The different situation in Portugal is probably due to the greater frequency of extra-residential help/care, which prevents employees carrying out this kind of tasks. These individuals who provide extra-residential help/care have higher incomes than the co-residential carers and the non-carers. This situation can be largely explained by the younger age of these individuals. As Netuveli et al. (2006) note, younger individuals have higher earnings in general.

In terms of health, Portuguese co-residential carers have a higher number of limitations in accomplishing their activities of daily living and they have a higher chance of depression than non-carers. Barrow and Harrison (2005) and De Koker (2009) found similar results in their research. They state that co-residential carers are more likely to suffer poor health. However, more recent studies contradict these conclusions, highlighting that only individuals with good health take on the role of informal carers (Herrera et al. 2013; Rösler-Schidlack et al. 2011). The health problems evidenced by the Portuguese co-residential carers may be related to the greater frequency and instrumentality of the care given in Portugal, as well as the lack of care structures and support policies for the carer. The individuals who frequently provide extra-residential help/care (daily or weekly help), compared with the non-carers group, are also more likely to suffer from depression and are no different from the latter in terms of the limitations to accomplishing their activities of daily living, when socio-demographics and other health variables are controlled. This result does not therefore corroborate the 'better health status' put forward by Barrow and Harrison (2005) for the north-west of England, probably due to the intensive nature of these tasks in Portugal. In short, co-residential care and the provision of frequent extra-residential help/care (daily or weekly) are associated with a higher number of depressive symptoms. These results confirm those of other studies, which state that co-residential care and/or care of a more intensive nature are associated with less mental health (Colombo et al. 2011) and that activities with a low level of autonomy and perceived control are associated with more depressive symptoms (Wahrendorf et al. 2008). The Portuguese context determines that co-residential carers and extra-residential helpers/ carers are also more subjected to tasks that demand a moderate or even intense physical effort than non-carers. Involvement in activities of a social nature also distinguishes the different groups of carers under analysis. Extra-residential helpers/carers participate in more social activities than co-residential carers. As evidenced by Burr et al. (2007), the time available for this type of activities is very limited in the case of co-residential carers involved in fulltime demanding tasks. The conditions in which co-residential care is provided in Portugal and the characteristics of the 50+ population explain, as predicted in one of the hypothesis of this study, the low QoL of co-residential carers. Yet, the provision of less-frequent (monthly or less frequent) extra-residential help/care is associated with a higher QoL.

The results highlight the role of retired people in the provision of informal support in Portugal, and the low level of physical and mental health of co-residential carers. In Portugal, both co-residential care and extra-residential help/care (everyday or every week help/care) have a negative impact on mental health, but these two kinds of support affect QoL differently: co-residential carers have the lowest QoL, and extra-residential (monthly or less frequent) carers have the highest QoL. This study demonstrates that the Portuguese 50+ population has an important role in the provision of co-residential care, and it is important for scientific research to differentiate the type and frequency of support, since this can help design policies to meet the specific needs of the various types of older informal carers.

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