Original Article

Associations between informal care, disease, and risk factors: A Spanish country-wide population-based study

Luís González-de Paz[a,b,*], Jordi Real[a,c], Alicia Borrás-Santos[a,d,e],
José M. Martínez-Sánchez[f,g,h], Virginia Rodrigo-Baños[b], and
María Dolores Navarro-Rubio[a,i,j]

[a]Facultat de Medicina i Ciencies de la Salut, Public Health Unit, School of Medicine and Health Sciences, Universitat Internacional de Catalunya, C. Doctor Trueta S/N, Sant Cugat del Vallès, Barcelona 08195, Spain.

[b]Centre d'Atenció Primària Les Corts. Transverse Group for Research in Primary Care, IDIBAPS, Barcelona, Spain.

[c]Institut d'Investigació en Atenció Primària Jordi Gol (IDIAP Jordi Gol). USR-Lleida, Lleida, Spain.

[d]Centro de Investigación Biomédica en Red Enfermedades Respiratorias (CIBERES), Madrid, Spain.

[e]Centre for Research in Environmental Epidemiology (CREAL), Barcelona, Spain.

[f]Biostatistics Unit, School of Medicine and Health Sciences, Universitat Internacional de Catalunya, Sant Cugat del Vallès Barcelona, Spain.

[g]Tobacco Control Unit, Cancer Prevention and Control Programme, Catalan Institute of Oncology-ICO, Hospitalet de Llobregat Barcelona, Spain.

[h]Cancer Control and Prevention Group, Bellvitge Biomedical Research Institute-IDIBELL, Hospitalet de Llobregat Barcelona, Spain.

[i]Albert Jovell Institute for Public Health and Patients. Universitat Internacional de Catalunya, Sant Cugat del Vallès Barcelona, Spain.

[j]Spanish Patient's Forum, Barcelona, Spain.

*Corresponding author. E-mail: gonzalezdepaz@hotmail.com

Abstract   This population-based study using 2011–2012 Spanish National Health Survey data aimed to measure the impact of disease, health-related habits, and risk factors associated with informal caregiving. We included and matched self-reported informal caregivers [ICs] with controls (1:4) from the same survey. For each outcome, we analyzed associations between ICs and controls using linear regression or logistic regression models. ICs had 3.4 per cent more depression (OR: 1.33, 95 per cent confidence intervals [CI]:1.06, 1.68). ICs had lower social support (95 per cent CI: 1.64, 3.28), they did more housework alone (OR:3.6,

95 per cent CI:2.65, 4.89), and had greater stress (95 per cent CI:0.13, 0.83). Women ICs caring alone had more anxiety than other groups. We found no statistical association between caregivers and worse health-related habits or increased risk factors (less physical activity, smoking, drinking, and cholesterol). Our results provide evidence that health-care professionals and organizations should recognize the importance of caring for those who care.

Introduction

Aging is associated with an increase in chronic and non-communicable diseases, and reduced functional and social independence.[1] When family members require care because of functional limitations, household roles change and relatives often become informal caregivers (ICs). They aid home maintenance and the activities of daily living, such as bathing, dressing, and eating.[2] The well-being of ICs influences the control of disease symptoms[3] and the quality of life of care receivers,[4] and is crucial to health budgets,[5,6] that could not afford nursing home care for all who might benefit from it. Examining epidemiologically the consequences of informal caregiving is relevant, as the regional office for Europe of the World Health Organization forecasts that, by 2050, people aged ⩾65 years will form >25 per cent of the population. They will, at some point, require a caregiver.[1]

Informal caregiving has social and health consequences. ICs often abandon social relationships, consider changing jobs or work schedules, and may suffer psychological distress and physical disease.[7,8] The negative outcomes, resulting from ICs feelings of inability to manage care receivers' demands, have been called the *caregiver's burden*.[9] Factors such as sex, age, socioeconomic status, educational attainment, ethnicity, social support, household organization, and time spent caring may also have an influence.[2,10,11] Current guidelines on dementia, degenerative diseases, and severe mental impairment include charters and information to reduce negative health-related outcomes for caregivers.[12–14] Effective support actions include assessing living conditions to educate ICs on environmental changes in the home, psycho-educational interventions to help ICs assimilate a more clinical belief set about their

role, and enhancement of coping skills.[3] These have been shown to lessen caregivers' burdens and improve the quality of life of ICs.[15]

Interventions with ICs aim to avoid disease and symptoms as ICs suffer more depression, anxiety, gastric disease, and a worsening in chronic conditions, plus health-related habits (smoking, drinking, and little physical activity) as compared with the general population. These differences may occur because ICs reduce their leisure time and abandon social relationships, which in turn affect health-related habits.[7,8,15,16] Most studies have concluded that the association between the disease burden and informal caregiving warrants further epidemiological study and analysis.[2]

Most studies have enrolled ICs by looking at groups of patients with specific conditions (Alzheimer's, the terminally ill, disabled children, and so on). Little is known about ICs in general.[10,17,18] Strong evidence of links between informal caregiving and disease would permit more effective interventions by health-care professionals aimed at protecting ICs – disease prevention and promoting a healthy household.

Does informal caregiving cause mental health problems, physical disease, and even increased mortality? Probably, but measures of the association with disease are not proven and come from studies with small sample sizes in special groups of caregivers.[2] The primary objective of our study was to learn whether informal caregiving was associated with disease and, secondarily, to examine differences in risk factors and health-related habits.

Methods

Study design

We undertook a matched cross-sectional study using a representative survey of Spanish households to describe the association between informal caregiving and health outcomes for the caregivers.

Hypothesis

On the basis of previous studies, we expected that ICs would have more depression and anxiety, worse health status, and would report fewer desirable health-related habits, compared with matched controls.

We expected that perceived social support would mediate the effect of depression and anxiety.

Data

The 2011–2012 Spanish National Health Survey, a survey conducted by the National Statistics Institute, collected information on the determinants and opinions of citizens about their health. It comprised three questionnaires: for household residents, for adults, and for children,[19] and provided a representative sample ($N = 21,007$) of Spain's non-institutionalized home-dwelling population. The units of analysis are Spanish households. A multistage cluster method with proportional random selection of primary and secondary sampling units (regions, towns, and census tracts, respectively) creates the sample, with the final sample selected by sex- and age-based quotas. Trained interviewers conducted the survey with face-to face interviews in homes. Methodological details have been published elsewhere.[19]

Participants and matching criteria

We used three criteria to identify eligible participants aged >15 years:

(1) having an individual with any functional limitation or disability, unable to self-care, in need of a caregiver (excluding normally-developing children) in the household;
(2) reporting being the sole or shared caregiver of the disabled resident;
(3) caregiving for >1 year (thus avoiding any disease bias with respect to the start of caring).

Once selected, each completed the Spanish National Health Survey health questionnaire. We selected four controls who did not report caring for anybody in the household for each IC among individuals completing the survey.

We matched ICs and controls using a propensity score, with the nearest neighbor method (caliper $= 0.2$, $r = 1:4$) to reduce bias because of confounding variables at the individual level and to produce a data set closer to that which would result from a block, randomized design.[20] We matched groups by age, sex, size of municipality, household composition, educational level, and household net monthly income.

Web Appendix I shows that the overall mean difference in the selected variables was reduced to almost 0 from the pre-matched sample to the final matched sample; each case was matched with a mean of four controls from the same Spanish region, and, therefore, comparability and representativeness was maximized. Web Appendix II shows the factors used to match ICs with controls: Percentages were similar in all variables and categories.

Variables

We defined four main outcomes:

(1) diagnosis of chronic depression;
(2) anxiety;
(3) perceived personal social support; and
(4) degree of psychological well-being.

To collect diagnosis of chronic depression or anxiety we used the question: 'Has your doctor ever told you that you suffer from (disease)?'.[19] To collect the perceived personal social support information, we used the Spanish adaptation of the DUKE-UNC Functional Social Support Questionnaire.[21] This is a self-administered 11-item questionnaire, with each item scored from 1 to 5. It assesses the degree of an individual's social interaction and subjective support. To measure the degree of psychological well-being, we used the Goldberg GHQ 12, [22]a 12-item scale, to identify the severity of an individual's psychological distress. It is used to assess mental health, covering disorders or patterns of adjustment associated with distress. Each scale item has four responses from 'better than usual' to 'much less than usual.'
    Secondary outcomes were:

- Quality of life, measured using the EQ-5D-5L questionnaire – a widely used instrument that assesses five self-perceived and health-related quality of life states (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression)[23] plus other health problems including mental problems (not depression or anxiety), migraine or frequent headaches, chronic constipation, ulcers (stomach or duodenum), and chronic back pain (lumbar or cervical).
- Drug use during the previous 2 weeks (of tranquilizers, muscle relaxants, sleeping drugs, antidepressants, stimulants) using the question:

'Have you taken this kind of drug in the past two weeks and, if so, what drugs have been prescribed by a doctor?'. This variable had two levels: drugs prescribed and drugs consumed.

- Health-related habits based on six risk factors targeted by the World Health Organization were assessed using National Health Survey questionnaire data:[24] medical diagnoses of diabetes (types 2 and 1), high blood pressure, and elevated total cholesterol; smoking (*current smoker, ex-smoker, never smoker*); physical activity (*low, medium, high*) was measured using the IPAQ questionnaire; chronic heavy drinking was determined by the mean units of alcohol per week (men $\geqslant 27$, women $\geqslant 14$).[25]

- Other variables. We studied type of care (caring alone or sharing care with others); the degree of participation in housework – measured using the question 'Who mainly does the housework such as washing, cooking, ironing, etc.?' answers classified as: *No housework (others do it), shared with another person*, or *alone;* current employment (*yes, no*).

- Stress and work satisfaction measured using a 7-point Likert scale.

Statistical methods

Continuous variables were expressed as means and standard deviation (SD) or medians plus 25th and 75th percentiles; categorical variables as percentages. The prevalence of household-dwellers with functional limitations or disability and of ICs in Spanish households were computed using the whole National Health Survey sample. We calculated the error and 95 per cent confidence intervals (CI) using weighting coefficients.

For all outcomes, we analyzed associations between ICs and controls using a linear regression model or a logistic regression model with clustered standard errors. We report results as a linear coefficient or an adjusted odds ratios (OR) with 95 per cent CI. We examined differences in stress and satisfaction at work in employed ICs. We studied the impact of disease in ICs according to sex for the type of caregiving: alone or shared. We reported the results as the prevalence ratio (PR) and 95 per cent CI. We studied the impact of depression and anxiety using a linear regression model, and reported results as a linear coefficient with 95 per cent CI.

We tested mediation effects (indirect) using bootstrap methods and adjusting by sex. We chose this method to prevent type I error, because

bootstrapping does not require the assumption of normality of the sampling distribution. It allows the indirect effect to be estimated using repeated samples from the data set, and produces bias-corrected accelerated confidence intervals for the indirect effect. After examining the bootstrap confidence interval, we calculated the ratio of the indirect effect to the total effect (*mediation ratio*).[26] In all analyses, the level of statistical significance was set at $\alpha = 0.05$. For the analysis we used SPSS v. 22th (IBM Corp) and R v. 3.1.2 statistical packages.[27,28]

Ethical considerations

Our study used information from a public data set. The Spanish National Statistics Institute asserted that all permissions and ethical concerns were guaranteed and all participants had consented to their information being published anonymously. These public data files contain anonymous information and assure participant confidentiality.[19] For these reasons, Ethics Committee approval was not required under Spanish legislation and European Union (EU) rules.

Results

An estimated 6.60 per cent (95 per cent CI: 5.90, 7.40) of Spanish households had a disabled resident requiring informal care. Five hundred fifteen (2.45 per cent) of ICs fulfilled our inclusion criteria. Women made up 63.1 per cent of these ICs, with a mean age of 58.01 years ($SD = 16.12$, range 17–96). Four hundred forty-three (86.01 per cent) were caring for one adult and 48 (9.32 per cent) were caring for children with limitations or disabilities (Table 1).

Table 2 shows the primary outcomes. ICs were more likely to have received a diagnosis of depression (3.4 per cent, $P<0.05$) and less social support ($P<0.001$) than controls. ICs had worse psychological well-being and more diagnoses of anxiety, although the results were not significantly different. We found a significant mediation effect on depression ($P<0.001$) from functional social support – 26.37 per cent of the total effect. The direct effect between caregiving and depression fell ($P=0.484$). The same result was found for anxiety: functional social support explained 35.45 per cent of the total effect of anxiety in caregivers (Table 2).

Table 1: Caregiver characteristics

Characteristics	(n = 515)
Who provides care	
Caregiving alone	302 (58.06%)
Sharing care	213 (41.40%)
Mean years providing care (SD)	17.96 (25.57)
25th–50th–75th percentiles	3–7–20
Mean care in hours, total week (SD)	55.37 (58.18)
25th–50th–75th percentiles	16–42–64
Reference person (main household provider)	231 (44.9%)
Age of care receiver by household	
Adult	467 (90.70%)
Child	47 (9.1%)
Adult and child	1 (0.20%)
Caregiver relationship with care receiver (N = 540)	
Spouse or partner	156 (28.90%)
Parents or in-laws	141 (26.1%)
Grandparents	3 (0.60%)
Son, daughter or son-in-law	170 (31.50%)
Other relative or unrelated	71 (13.10%)
Occupational status	
Working	127 (24.70%)
Unemployed	73 (14.205%)
Housework	110 (21.40%)
Retired	170 (3.35%)
Other	35 (6.90%)
Marital Status n (%)	
Single	115 (22.30%)
Married	320 (62.10%)
Widowed	45 (8.70%)
Legally separated or divorced	35 (6.80%)
High risk drinking	
Women	10 (3.1%)
Men	17 (8.9%)
Physical activity	
Low	160 (46.90%)
Moderate	110 (32.30%)
Vigorous	71 (20.80%)

Secondary outcomes (Table 3) showed that quality of life was very similar in the two groups, except for the anxiety and depression dimensions in the questionnaire ($P<0.001$). Unexpectedly, there were

Table 2: Results of primary outcomes.

Primary outcomes	Informal caregivers n = 515	Controls n = 2053	P-value	Measure of association	95% CI
Functional social support, Mean (SD)	45.68 (9.48)	48.14 (8.14)	<0.001	2.46[a]	1.64, 3.28
Psychological well-being (Goldberg GHQ 12)	3.50 (11.66)	3.40 (12.92)	0.871	0.10[a]	−1.34, 1.14
Medical diagnosis (yes)					
Chronic depression	81 (15.7%)	252 (12.3%)	0.012	1.334[b]	1.06, 1.68
Chronic anxiety	70 (13.6%)	230 (11.2%)	0.094	1.247[b]	0.96, 1.62
Functional social support as a mediator of depression[c]					
Effect of caregiving (direct effect)	–	–	0.484	1.32	1.00, 1.74[d]
Effect of functional social support (indirect effect)	–	–	<0.001	2.08	1.03, 1.13[d]
Functional social support as a mediator of anxiety[c]					
Effect of caregiving (direct effect)	–	–	0.161	1.23	0.85, 1.64
Effect of functional social support (indirect effect)	–	–	<0.001	1.07	1.04, 1.13

[a]Regression coefficient.
[b]Odds ratio.
[c]Mediating analyses were carried out by adjusting the outcome (depression and anxiety) by sex.
[d]Bootstrap 95 per cent CI with 1000 resamples.

non-significant results in outcomes previously reported to affect ICs – migraine, digestive disorders, and chronic back pain. ICs were more likely to report doing housework alone (53.20 per cent ICs versus 30 per cent of controls). Working ICs had more stress at work than controls ($P = 0.003$), but satisfaction was similar in both groups. There were no significant differences in the proportions of the two groups with diabetes diagnoses, high blood pressure, elevated cholesterol, smoking, risky drinking, or low physical activity (Table 4).

Women caregivers had a higher prevalence of depression (PR:3.36; 95 per cent CI:1.87, 6.04) and anxiety (PR:3.51; 95 per cent CI: 1.84, 6.69) than men. Caring alone had significant indirect effect on anxiety in women ICs (OR: 1.02, 95 per cent CI: 1.01, 1.04). Caring alone accounted for 17.91 per cent of the likelihood of anxiety ($P = 0.01$). Caring alone had a non-significant indirect effect on depression (OR: 0.99, 95 per cent CI: 0.97, 1.01, $P = 0.591$). Hours of informal care per week were not associated with the likelihood of depression (regression coefficient: 0.002, 95 per cent CI: −0.00, 0.01, $P = 0.525$), but a statistical trend was found in the likelihood of anxiety

Table 3: Results of the secondary outcomes

Secondary outcomes	Informal caregivers n = 515	Controls n = 2053	P-value	Measure of association	95 per cent CI
Euroqol-Quality of Life: Mean (SD)					
Mobility	1.38 (0.80)	1.41 (0.85)	0.444	0.034[a]	0.12, 0.05
Self-care	1.13 (0.49)	1.17 (0.61)	0.058	0.04[a]	−0.09, 0.0
Usual activities	1.28 (0.70)	1.31 (0.76)	0.437	−0.03[a]	−0.10, 0.04
Pain, discomfort	1.63 (0.94)	1.61 (0.92)	0.919	0[a]	−0.07, 0.07
Anxiety, depression	1.45 (0.87)	1.31 (0.78)	<0.001	0.14[a]	0.06, 0.23
Medical diagnosis (yes)					
Other mental problems	11 (2.1%)	34 (1.7%)	0.418	1.296[b]	0.68, 2.46
Migraine or frequent headaches	66 (12.8%)	244 (11.9%)	0.569	1.090[b]	0.81, 1.47
Ulcers (stomach or duodenum)	34 (6.6%)	132 (6.4%)	0.344	1.164[b]	0.84, 1.60
Chronic back pain (lumbar or cervical)	160 (31.1%)	712 (34.7%)	0.238	1.090[b]	0.94, 1.26
Drug use and suitability					
Tranquilizers, muscle relaxants, and sleeping drugs.					
Consumed	91 (17.7%)	332 (16.2%)	0.317	1.112[b]	0.90, 1.37
Prescribed	91 (17.7%)	323 (15.7%)	0.427	1.141[b]	0.82, 1.59
Antidepressants and stimulants					
Consumed	45 (8.7%)	159 (7.7%)	0.427	1.141[b]	0.82, 1.59
Prescribed	45 (8.7%)	159 (7.7%)	0.427	1.141[b]	0.82, 1.59
Housework					
No (others do it)	86 (16.70%)	695 (33.90%)	–	–	–
Shared with another person	155 (30.10%)	743 (36.20%)	0.008	1.686[b]	1.14, 2.50
Alone	274 (53.20%)	615 (30.00%)	<0.001	3.600[b]	2.65, 4.89
	n = 123	n = 633	–	–	–
Stress at work	4.58 (1.37)	4.13 (1.79)	0.007	0.48[a]	0.13, 0.83
Satisfaction at work	5.76 (1.37)	5.60 (1.36)	0.366	0.105[a]	−0.12, 0.33

[a]Regression coefficient.
[b]Odds ratio.

(regression coefficient: 0.005, 95 per cent CI: −6.604, 0.011, $P = 0.053$). Years providing care were not correlated with depression (regression coefficient: 0.01, 95 per cent CI:−0.01, 0.02, $P = 0.323$) or anxiety (regression coefficient: 0.004, 95 per cent CI −0.01, 0.02, $P = 0.408$).

Discussion

Our findings showed that ICs were more likely to have chronic depression than matched controls. Prevalence of disease in ICs was mediated by two factors: sex and caring alone. The latter also affected the likelihood of anxiety. The time spent caring did not have a significant effect.

Table 4: Differences in health-related habits and risk factors between ICs and control group

Health-related habits and risk factors	Informal caregivers n = 515	Controls. n = 2053.	P-value	Measure of association	95% CI
Diabetes (Type 2 and 1)	67 (13.0%)	227 (11.1%)	0.171	1.203[a]	0.92, 1.57
High blood pressure	160 (31.10%)	713 (34.13%)	0.099	0.847[a]	0.70, 1.03
Elevated cholesterol	143 (27.80%)	550 (26.80%)	0.648	1.050[a]	0.85, 1.30
Smoking					
No	298 (57.90%)	1228 (59.80%)	–	–	–
Current smoker	115 (22.30%)	424 (20.70%)	0.409	1.118[a]	0.86, 1.46
Ex-smoker	102 (19.80%)	401 (19.50%)	0.791	1.048[a]	0.74, 1.49
Physical activity					
Low	160 (46.90%)	642 (47.90%)	–	–	–
Medium	110 (32.30%)	430 (32.10%)	0.801	1.026[a]	0.84, 1.26
High	71 (20.80%)	26p (20.10%)	0.708	1.059[a]	0.78, 1.43
Risk drinking	27 (5.20%)	97 (4.70%)	0.624	0.896[a]	0.58, 1.39

[a]Odds ratio.

Other factors affecting ICs were lower perceived functional social support, greater stress at work, and doing more housework.

ICs were more likely to have chronic depression than controls (OR 1.3). In a systematic review of studies of caregivers for dementia patients, the relative risk of depression ranged from 2.80 to 38.68.[29] The most recent Spanish study reported that major depressive symptoms affected 8.9 per cent of ICs.[30] The variations in impact may be due to the criteria used to establish a diagnosis of depression and the groups of ICs studied. We found that social support was a full mediator between caregiving and impact of depression. A similar effect was found for anxiety. Thus we believe that social support is essential to explain impact of depression and anxiety in caregivers, as reported.[11] The negative consequences of caring worsens if caregivers lack family support in the household, and have to undertake all the housework.[31,32] Links between the household organization and housework were also reported in a recent study in 12 European countries.[33] Interestingly, in our study, the time spent on informal caring was not associated with self-reported poor health, as found by other studies.[34]

We found none of the expected differences in risk factors and health-related habits between caregivers and controls that have been reported by other studies in which physical activity or dietary habits affected cholesterol levels or diabetes.[15,17,18,35] We found no significant

differences between caregivers and matched controls in diabetes diagnoses, high blood pressure, elevated cholesterol, or health habits. The lack of control groups in previous studies, and associations based on the Zarit Burden Inventory scores – a widely used self-report instrument designed to reflect the negative experience of caregivers – may explain these differences. The Zarit inventory overlaps in several dimensions, and was not designed to detect diseases as coded in the International Disease Classification.[2]

Our results suggest that health-care professionals should focus on caregivers' perceptions of social isolation and the symptoms of depression and anxiety. In dementia and cancer guidelines, the British National Institute for Health and Care Excellence advises health professionals to determine the central role of ICs and their need for support.[12,13] Health-care professionals should seek to identify systematically any psychological distress or psychosocial impact associated with caring. Health-care professionals might explore how to involve other family members in care plus the caregiver's needs. Health-care organizations should arrange links with other organizations to develop and deliver services for ICs and offer support and information. The evidence on health-care interventions to reduce stress among ICs, such as meditation or cognitive therapy, might be evaluated, although the current level of evidence is low.[36]

Given the crucial tasks and social relevance of ICs, support for ICs should be available when recipients of care have any conditions that require assistance with activities of daily living. Currently, schemes of support for ICs are in place in the 27 EU countries.[37] Almost all offer counseling to reduce caregivers' stress, information plans, respite care programs, and training delivered through health systems. The most common are respite programs that facilitate temporary breaks for ICs by admitting the recipient of care to nursing homes.[38] A systematic review of respite programs for caregivers where the care recipient has dementia, found no significant effects of these programs. Additional research is needed to address the range of interventions and conditions for which caregivers may provide care.[39] While ICs needs are considered, a recent review of policies across EU countries noted that there is no evaluation system to measure the effect of these programs.[37] The financial support offered to ICs is not as uniform as health-care support. In Spain, IC support varies based on the level of disability of care recipients. Budget cuts during the recent financial crisis have

resulted in ICs receiving financial support only when care recipients are severely dependent.[40]

Study limitations and strengths

The survey method may result in bias. Diseases and diagnoses were self-reported to trained professionals, who, to maximize reliability, used a computer-assisted personal interviewing method. Our cross-sectional design meant we were unable to determine whether diseases developed after or before informal caregiving began. This potential bias affected both ICs and controls. Other results supported the findings: depression-anxiety scores from the quality of life questionnaire were worse compared with controls. The mediation analysis may be affected by temporal precedence: if the ICs had less social support before becoming a caregivers, this would suggest a directional link. In analysis of mediation, there was theoretical and empirical evidence of the mediation relationship between social support and the anxiety and depression.

The strengths of the study were the sample size and the heterogeneity of ICs that permitted a view not restricted to a specific disease. The data came from a national survey. This allows correct inference and generalization of results, and ICs matched with controls allowed us to minimize potential confounding issues. These methods closely emulated an experimental design with random selection.

Policy conclusions

In this study, ICs had a greater prevalence of depression after adjusting for social and demographic determinants of health. Women caring alone had a greater likelihood of anxiety and depression, independent of the time spent caring. Health-care professionals should take the symptoms and signs of depression among ICs into account. ICs may require more health-care attention and social support. More scientific evidence, program development, and evaluation are needed to provide adequate health care to all ICs. Health-care organizations and clinical guidelines should make support for ICs more explicit.

Policymakers might address two important issues: establishment of standard welfare benefits according to the health status of caregivers – not only the care receiver – and a set of indicators to assess the effectiveness of current programs.

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About the Authors

Luis Gonzáles-de Paz, PhD, MSc, R.N. is a researcher in the Transverse Group for Research in Primary Care, Institut d'Investigació Biomèdica August Pi i Sunyer (IDIBAPS), Barcelona, Spain. He lectures in the Universitat Internacional de Catalunya, Sant Cugat del Vallès (Barcelona), Spain.

Jordi Real is a statistician in Institut d'Investigació en Atenció Primària Jordi Gol (IDIAP Jordi Gol), Lleida, Spain. He lectures in the Universitat Internacional de Catalunya, Sant Cugat del Vallès (Barcelona), Spain.

Alicia Borrás-Santos is a researcher in the Centre for Research in Environmental Epidemiology (CREAL), Barcelona, Spain. She lectures in the Universitat Internacional de Catalunya, Sant Cugat del Vallès (Barcelona), Spain.

José M. Martínez-Sánchez is a researcher in the Cancer Control and Prevention Group, Bellvitge Biomedical Research Institute-IDIBELL, Hospitalet de Llobregat (Barcelona), Spain. He is the head of the Biostatistics Unit in the Universitat Internacional de Catalunya, Sant Cugat del Vallès (Barcelona), Spain.

Virginia Rodrigo-Baños is a community and family nurse resident in Les Corts Primary Health Care Center, Barcelona, Spain.

María Dolores Navarro-Rubio is the head of the public health and epidemiology department. She is the director of the Albert Jovell Institute for Public Health and Patients in the Universitat Internacional de Catalunya, Sant Cugat del Vallès, (Barcelona), Spain.

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