

# Cuidado informal y principales determinantes de la carga soportada por los cuidadores de supervivientes de ICTUS en España

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# Contexto

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- Ictus: enfermedad cerebrovascular que se produce como consecuencia de la ruptura (ictus hemorrágico) o taponamiento (ictus isquémico) de un vaso sanguíneo que lleva sangre al cerebro.
  - Consecuencias: elevada mortalidad e importantes secuelas en los supervivientes.
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# Contexto

GBD 2015 DALYs and HALE Collaborators. Lancet 2016; 388

Leading causes 1990	Leading causes 2005	% change, number of DALYs 1990-2005	% change, all-age DALY rate 1990-2005	% change, age-standardised DALY rate 1990-2005	Leading causes 2015	% change, number of DALYs 2005-15	% change, all-age DALY rate 2005-15	% change, age-standardised DALY rate 2005-15
1 Lower respiratory infection	1 Ischaemic heart disease	26.3	2.7	-12.2	1 Ischaemic heart disease	11.0	-1.8	-14.2
2 Neonatal preterm birth	2 Lower respiratory infection	-37.2	-49.0	-37.5	2 Cerebrovascular disease	0.1	-11.3	-22.2
3 Diarrhoeal diseases	3 Cerebrovascular disease	21.6	-1.0	-13.0	3 Lower respiratory infection	-23.8	-32.6	-31.0
4 Ischaemic heart disease	4 Neonatal preterm birth	-37.9	-49.4	-36.1	4 Low back and neck pain	18.6	4.9	-2.1
5 Cerebrovascular disease	5 HIV/AIDS	584.8	445.2	446.8	5 Neonatal preterm birth	-24.4	-33.1	-28.6
6 Neonatal encephalopathy	6 Diarrhoeal diseases	-37.3	-49.0	-39.3	6 Diarrhoeal diseases	-27.2	-35.7	-34.0
7 Malaria	7 Malaria	20.7	-1.4	18.3	7 Sense organ diseases	25.2	9.9	0.6
8 Measles	8 Low back and neck pain	34.5	9.4	-1.8	8 Neonatal encephalopathy	-14.6	-24.2	-19.2
9 Congenital anomalies	9 Neonatal encephalopathy	-2.4	-20.4	0.3	9 Road Injuries	-6.5	-17.1	-17.6
10 COPD	10 Road Injuries	11.8	-9.0	-7.9	10 HIV/AIDS	-32.6	-40.4	-40.3
11 Road Injuries	11 COPD	-1.1	-19.6	-27.7	11 Diabetes	29.0	14.6	1.6
12 Low back and neck pain	12 Congenital anomalies	-13.1	-28.3	-13.4	12 COPD	0.1	-11.5	-22.1
13 Tuberculosis	13 Sense organ diseases	39.4	11.7	2.1	13 Congenital anomalies	1.3	-9.4	-5.5
14 Iron-deficiency anaemia	14 Iron-deficiency anaemia	13.8	-10.0	-1.3	14 Malaria	-38.3	-45.0	-43.1
15 Protein-energy malnutrition	15 Tuberculosis	-15.0	-30.5	-35.8	15 Depressive disorders	18.2	4.5	1.0
16 Sense organ diseases	16 Diabetes	65.1	34.4	18.3	16 Iron-deficiency anaemia	-3.3	-17.2	-11.3
17 Drowning	17 Depressive disorders	32.9	8.1	0.6	17 Skin diseases	12.3	-0.7	0.6
18 Meningitis	18 Skin diseases	22.7	-0.2	1.2	18 Tuberculosis	-19.0	-28.2	-32.4
19 Depressive disorders	19 Self-harm	14.8	-6.8	-10.9	19 Lung cancer	14.5	1.1	-11.3
20 Skin diseases	20 Lung cancer	31.7	7.4	-6.1	20 Chronic kidney disease	19.6	4.8	-3.0

# Objetivo

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El objetivo es identificar variables explicativas y predictivas:

(i) la probabilidad de recibir cuidado informal entre las personas que sobreviven a un ictus

(ii) análisis de la carga de las personas cuidadoras

(iii) análisis de riesgo de claudicación (burnout) de las personas cuidadoras

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# Métodos

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- CONOCES: Costes socioeconómico del ictus en España
  - Estudio de carácter observacional, multicéntrico y prospectivo.
  - Pacientes con diagnóstico clínico del primer ictus establecido, isquémico o hemorrágico, con menos de 24 horas de evolución que ingresaron en unidad de ictus.
  - Dieciséis unidades de ictus de todas las CCAA excepto la Rioja, Ceuta y Melilla, participaron en el estudio
  - El número total de pacientes incluidos en el estudio general es de 320 pacientes.
  - Tres ventanas de observación: basal; 3 meses; 12 meses
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# Métodos

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- Variables explicativas y predictivas:
    - (i) Variables clínicas: escala NHISS de severidad del ictus (3 niveles)
    - (ii) Escala de dependencia funcional: índice de Barthel
    - (iii) CVRS: EQ-5D
    - (iv) Presencia o no de fibrilación auricular
    - (v) tiempo de cuidado (carga & burnout)
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# Métodos

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- Análisis estadístico:

Probabilidad de recibir cuidado (8 modelos)

Modelos a 3 y a 12 meses

Prob (receiving informal caregiving 3 months after hospital discharge)<sub>i</sub> =  $\beta_0 + \beta_1$  (patient age) +  $\beta_2$  (patient gender) +  $\beta_3$  (patient educational level) +  $\beta_4$  (main explanatory variable) +  $u_t$

Prob (receiving informal caregiving 12 months after hospital discharge)<sub>i</sub> =  $\beta_0 + \beta_1$  (patient age) +  $\beta_2$  (patient gender) +  $\beta_3$  (patient educational level) +  $\beta_4$  (main explanatory variable) +  $u_t$

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# Métodos

- Análisis estadístico:
- Carga del cuidador (10 modelos)
- Modelos a 3 y a 12 meses

Zarit score (at 3 months post-stroke) $i = \beta_0 + \beta_1$  (patient age) +  $\beta_2$  (patient gender) +  $\beta_3$  (patient educational level) +  $\beta_4$  (main explanatory variable) +  $u_t$ .

Zarit score (at 12 months post-stroke) $i = \beta_0 + \beta_1$  (patient age) +  $\beta_2$  (patient gender) +  $\beta_3$  (patient educational level) +  $\beta_4$  (main explanatory variable) +  $u_t$ .



# Métodos

- Análisis estadístico:
- Riesgo de claudicación-burnout (10 modelos)
- Modelos a 3 y a 12 meses
- Prob burnout (at 3 months post-stroke) $i = \beta_0 + \beta_1$   
(patient age) +  $\beta_2$  (patient gender) +  $\beta_3$  (patient  
educational level) +  $\beta_4$  (main explanatory variable) +  $u_t$ .
- Prob burnout (at 12 months post-stroke) $i = \beta_0 + \beta_1$   
(patient age) +  $\beta_2$  (patient gender) +  $\beta_3$  (patient  
educational level) +  $\beta_4$  (main explanatory variable) +  $u_t$ .

# Resultados (perfil)

	<b>3 months post-stroke</b>	<b>12 months-post stroke</b>
Caregivers included	224	202
Age (years)	55.24 (16.5)	56.35 (15.21)
Female	158 (70.53%)	143 (71.5%)
Relationship patient- primary caregiver		
Husband / Wife / Partner	100 (44.8%)	93 (46.0%)
Son / Daughter	88 (39.4%)	73 (36.1%)
Zarit score (primary caregiver)	45.74 (15.8%)	43.37 (15.9%)
Secondary caregiver	91 (40.6%)	67 (33.2%)

# Resultados (tiempo de cuidado)

3 months post-stroke				12 months post-stroke			
	Average daily informal care time (SD)	% of time of primary caregiver	% of total informal care time		Average daily informal care time (SD)	% of time of primary caregiver	% of total informal care time
Community activities	1.5 (1.4)	20.55%	17.1%	Community activities	1.8 (2.0)	27.78%	24.2%
Housework	1.9 (2.0)	26.03%	21.9%	Housework	1.4 (2.1)	21.59%	18.8%
Personal care	1.5 (2.4)	20.55%	17.8%	Personal care	1.8 (2.8)	28.57%	24.9%
Accompanying/ Supervision	2.4 (3.1)	32.88%	28.2%	Accompanying/ Supervision	1.4 (1.2)	22.06%	19.2%
Total primary caregiver (n=224)	7.3 (5.4)	100.00%	83.9%	Total primary caregiver (n=202)	6.3 (5.4)	100.00%	87.0%
Other caregivers (n=91)	3.4 (3.3)		16.1%	Other caregivers (n=67)	2.9 (3.4)		13.0%
Total informal care (primary + other caregivers) (n=224)	8.7 (6.5)		100.0%	Total informal care (primary + other caregivers) (n=202)	7.2 (6.1)		100.0%

# Resultados (prob recibir cuidados)

Dependent variable: receiving care	Explanatory variables	N	Marginal effect	SD	z	CI
At 3 months						
Model 1	Barthel Index $\geq 90$	273	0.002	0.058	0.04	(-0.112; 0.117)
Model 2	HRQoL mild (0.510-0.750 points)	260	0.045	0.062	0.70	(-0.077; 0.168)
	HRQoL high ( $>0.750$ points)	260	<b>-0.225</b>	0.071	-3.37	<b>(-0.365; -0.085)</b>
Model 3	NIHSS at discharge moderate or severe	274	0.053	0.049	1.05	(-0.04; 0.150)
Model 4	AF	274	0.026	0.050	0.53	(-0.072; 0.126)
At 12 months						
Model 1	Barthel Index $\geq 90$	246	-0.035	0.063	-0.54	(-0.159; 0.087)
Model 2	HRQoL mild (0.510-0.750 points)	238	0.027	0.068	0.39	(-0.107; 0.162)
	HRQoL high ( $>0.750$ points)	238	<b>-0.217</b>	0.073	-3.10	<b>(-0.361; -0.073)</b>
Model 3	NIHSS at discharge moderate or severe	248	<b>0.110</b>	0.048	2.06	<b>(0.014; 0.205)</b>
Model 4	AF	248	0.068	0.052	1.29	(-0.034; 0.170)

# Resultados (carga)

Dependent variable (Zarit score)	Description of explanatory variables	N	Marginal Effect	SD	z	CI
At 12 months post-stroke						
Model 1	> 3 and ≤ informal care 6 daily hours	186	9.103	3.218	2.83	(2.794; 15.412)
	> 6 and ≤ 10 informal care daily hours	186	9.533	4.629	2.06	(0.459; 18.607)
	> 10 informal care daily hours	186	11.726	3.138	9.74	(5.575; 17.877)
Model 2	Barthel Index ≥ 90	185	-11.057	3.262	-3.39	(-17.452; -4.662)
Model 3	HRQoL mild (0.510-0.750 points)	181	-8.407	3.125	-2.69	(-14.5344; -2.281)
	HRQoL high (> 0.750 points)	181	-13.988	3.001	-4.66	(-19.871; -8.106)
Model 4	NIHSS at discharge moderate or severe	186	8.521	2.577	3.31	(3.469; 13.574)
Model 5	AF	186	6.382	2.36	2.70	(1.743; 11.022)

# Resultados (riesgo de burnout)

Dependent variable (Risk of burnout)	Description of explanatory variables	N	Marginal Effect	SD	z	CI
At 12 months post-stroke						
Model 1	> 3 and ≤ informal care 6 daily hours	186	0.200	0.11	2.16	(0.000; 0.400)
	> 6 and ≤ 10 informal care daily hours	186	0.192	0.143	1.52	(-0.088; 0.473)
	> 10 informal care daily hours	186	0.298	0.093	3.44	(0.115; 0.482)
Model 2	Barthel Index ≥ 90	185	-0.158	.081	-2.11	(-0.318; 0.000)
Model 3	HRQoL mild (0.510-0.750 points)	181	-0.132	0.058	-2.13	(-0.246; -0.017)
	HRQoL high (> 0.750 points)	181	-0.230	0.053	-3.53	(-0.335; -0.124)
Model 4	NIHSS at discharge moderate or severe	186	0.213	0.067	3.32	(0.082; 0.345)
Model 5	AF	186	0.066	0.059	1.11	(-0.050; 0.183)

# Conclusiones

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- Principal aportación
  - Identificamos una serie de variables que ayudan a explicar la provisión de cuidado informal y la carga de las personas cuidadoras.
  - Variables predictivas (momento basal)
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# Conclusiones

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- Identificar herramientas que (i) ayuden a predecir la probabilidad de que un sobreviviente de un accidente cerebrovascular necesite atención informal; (ii) ayudar a predecir que el cuidador está en riesgo de una carga significativa
  - Reforzar estrategias para responder a las necesidades específicas de los cuidadores (especialmente para aquellos con accidente cerebrovascular grave)
  - Reforzar las estrategias para centrarse en la promoción del bienestar y la calidad de vida de los sobrevivientes (para aquellos con apoplejía moderada o leve)
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Muchas gracias por su atención

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