



Conférence *Les Aidants*
Mardi 8 février 2011

Besoins d'aide et composition de l'aide reçue par les personnes âgées en domicile ordinaire.
Une estimation à partir des enquêtes Handicap-Santé Ménages et Handicap-Santé Aidants 2008

Bérengère DAVIN, Alain PARAPONARIS, Gwendoline TACHE



alain.paraponaris@inserm.fr

BACKGROUND



Population ageing in France

60 years and older in the whole population

2000: 12.1 million (20.6%)

2010: 14.1 million (22.7%)

2060: 23.6 million (32.1%)

Dementia in France

Alzheimer's disease accounts for 70% of forms of dementia

Prevalence estimated at 850,000 (85% aged 75 years and older)

Incidence estimated at about 220,000 new cases per year

Inserm, 2006

Family and informal caregivers

60% of people with dementia live in the community, mainly supported by informal caregivers

Impact of care on carers' mental and physical health and on carers' career

Helmer, 2003

Annual cost of informal care: 12,900€ for a person with dementia

Davin, 2009

Perspectives

Ageing of the French population and increase of the number of people with dementia

	2010	2020	2050
People aged 75 years and older in the French pop	8.8%	9.1%	15.6%
People with dementia	850,000	1,300,000	1,800,000

INSEE, 2010

Berr, 2010

Decrease of the number of informal carers

MAIN LINES

(1) Needs for human assistance with activities of daily living for elderly with and without Alzheimer Disease or Related Dementia (ADRD)

Socio-demographic characteristics

Needs for personal assistance with daily activities

Composition of human assistance (formal / informal / mixed / no care)

(2) Informal carers of elderly with and without ADRD

Socio-demographic characteristics of informal caregivers

Amount of informal care (care hours)

Impact of caregiving on carers' life and health



(1) NEEDS FOR HUMAN ASSISTANCE WITH ACTIVITIES OF DAILY LIVING FOR ELDERLY WITH AND WITHOUT ADRD



Sample

Data from the French national survey on health and disability (HSM, 2008)

396 elderly aged 60 years and older with reported ADRD, 336 individuals with attributed ADRD

Prevalence of ADRD in the community

369,000 individuals, IC95%=[338,321;399,849] (CNAMTS: 240,000; PAQUID: 480,000)

4,678 people aged 75 years and older living at home

ADRD: 513 individuals (reported ADRD: 320, attributed ADRD: 193)

No ADRD: 4,165 individuals

Weighted samples (representative of the reference population)

Variables

Socio-demographic characteristics: gender, age, education, household, income...

Health and disability : reported health, chronic diseases, cognitive functions

Type of care received: informal, formal, mixed, no care

Proxy respondent

Needs for human assistance with daily activities

7 ADLs

bathing, dressing, eating, using toilets

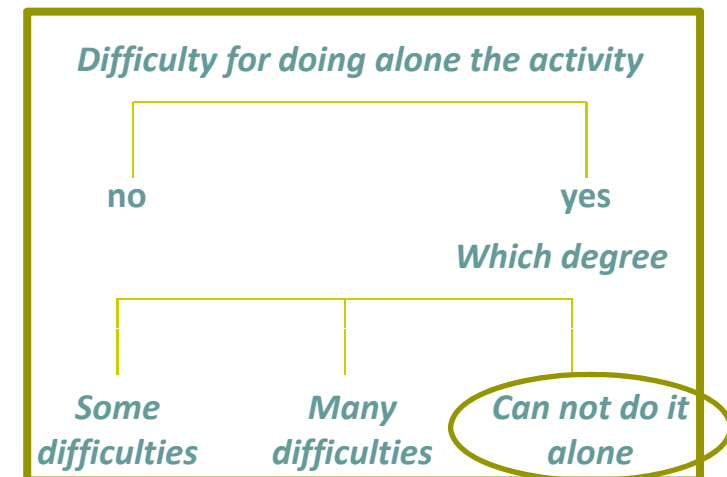
transferring from bed or chair, moving inside, moving around

8 IADLs

shopping, preparing meals, doing light housework

doing occasional housework, administrative management

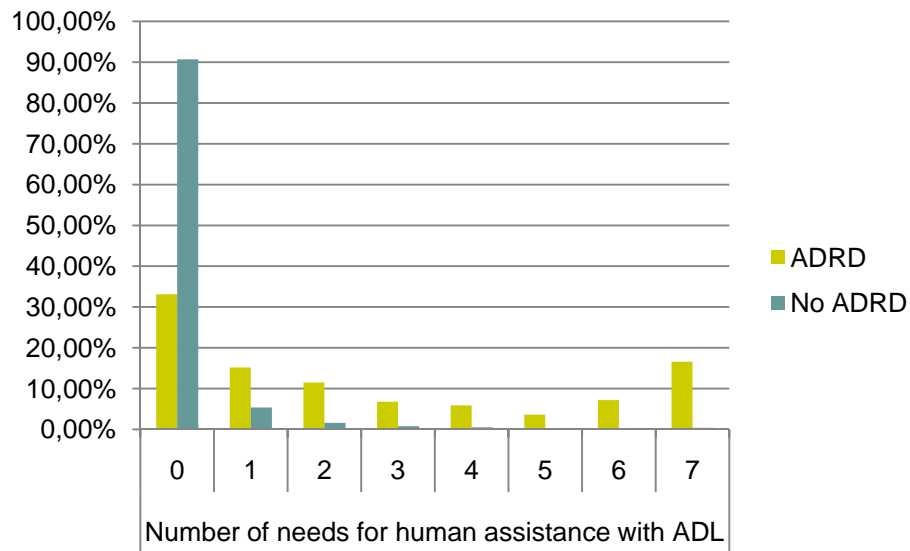
taking medications, using transports, using the telephone



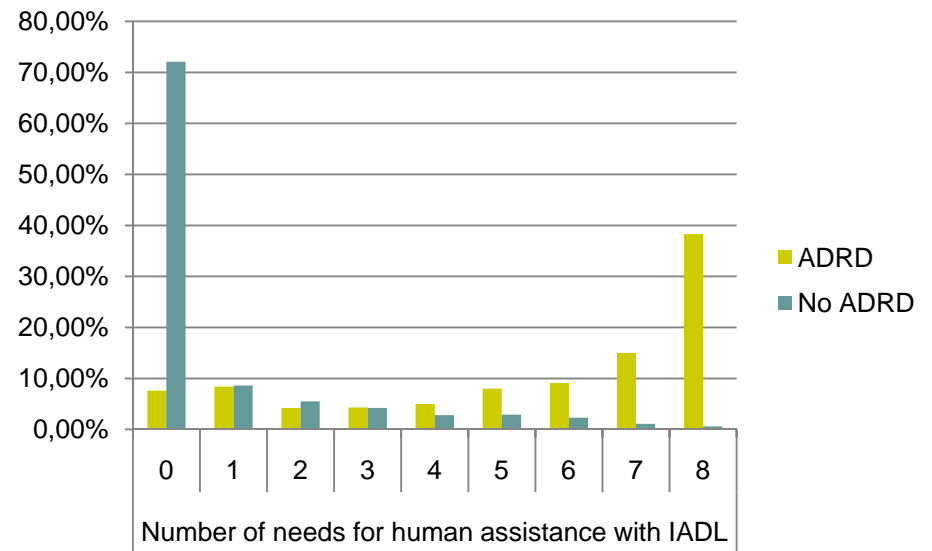
(1) NEEDS FOR HUMAN ASSISTANCE WITH ACTIVITIES OF DAILY LIVING FOR ELDERLY WITH AND WITHOUT ADRD



Distribution of number of needs for human assistance with ADL and IADL, individuals aged 75 years and older with ADRD (n=513) and with no ADRD (n=4,165)



P-value for Khi-2 comparison test: <.001



P-value for Khi-2 comparison test: <.001

(1) NEEDS FOR HUMAN ASSISTANCE WITH ACTIVITIES OF DAILY LIVING FOR ELDERLY WITH AND WITHOUT ADRD



Prevalence (%) of need for human assistance with ADL, individuals aged 75 years and older with ADRD (n=513) and with no ADRD (n=4,165)

ADL (%)	Elderly with ADRD	Elderly with no ADRD	Pvalue
Moving around	53.1	6.6	.000
Bathing	49.6	4.9	.000
Dressing	39.5	2.5	.000
Transferring from bed or chair	28.9	1.3	.000
Moving inside	27.3	1.3	.000
Using toilets	25.5	.9	.000
Eating	11.9	.3	.000
At least one ADL	66.9	9.3	.000

At least one ADL

Elderly with ADRD: 178,856 individuals (IC95%=[167,979; 189,732])
 Elderly with no ADRD: 418,585 individuals (IC95%=[378,892; 458,278])
 Total: 597,441 individuals (IC95%=[546,871; 648,010])

(1) NEEDS FOR HUMAN ASSISTANCE WITH ACTIVITIES OF DAILY LIVING FOR ELDERLY WITH AND WITHOUT ADRD



Prevalence (%) of need for human assistance with IADL, individuals aged 75 years and older with ADRD (n=513) and with no ADRD (n=4,165)

IADL (%)	People with ADRD	People with no ADRD	Pvalue
Administrative management	79.0	9.9	.000
Shopping	76.2	16.7	.000
Using transports	72.7	12.9	.000
Doing occasional housework	72.2	19.1	.000
Doing light housework	64.6	10.9	.000
Preparing meals	62.5	5.7	.000
Taking medications	61.5	2.2	.000
Using the telephone	47.1	1.4	.000
At least one IADL	90.0	26.3	.000

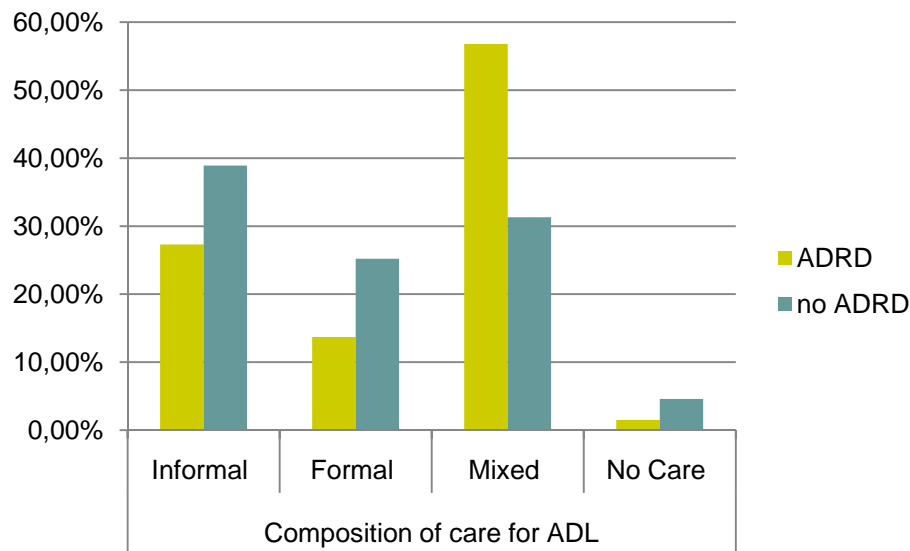
At least one IADL

Elderly with ADRD: 246,812 individuals (IC95%=[240,665; 252,958])
 Elderly with no ADRD: 1,258,912 individuals (IC95%=[1,197,117; 1,320,257])
 Total: 1,499,765 individuals (IC95%=[1,436,219; 1,563,310])

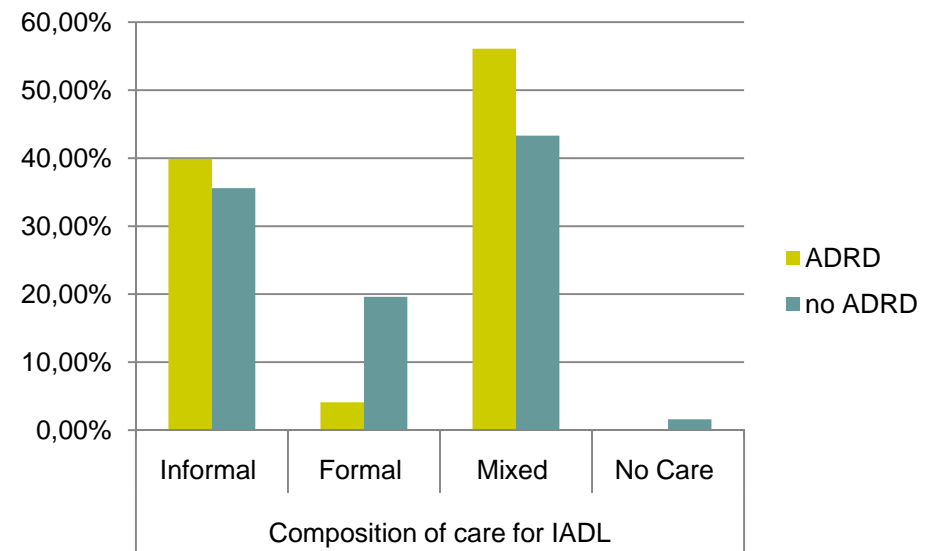
(1) NEEDS FOR HUMAN ASSISTANCE WITH ACTIVITIES OF DAILY LIVING FOR ELDERLY WITH AND WITHOUT ADRD



Composition of care (%) for ADL and IADL, individuals aged 75 years and older with ADRD (n=513) and with no ADRD (n=4,165)



P-value for Khi-2 comparison test: <.001



P-value for Khi-2 comparison test: <.001

(1) NEEDS FOR HUMAN ASSISTANCE WITH ACTIVITIES OF DAILY LIVING FOR ELDERLY WITH AND WITHOUT ADRD



Are discrepancies between elderly with and without ADRD:

only due to Alzheimer disease (share effect)?

partly due to some characteristics other than Alzheimer disease (shift effect)?

Sample characteristics, individuals aged 75 years and older with ADRD (n=513) and with no ADRD (4,165)

Variable	Characteristics	People with ADRD	People with no ADRD	P-value
Gender	Male	33.6%	37.6%	.237
	Female	66.4%	62.4%	
Age	From 75 to 79	19.7%	43.6%	.000
	From 80 to 84	34.9%	34.8%	1.000
	85 and older	45.3%	21.7%	.000
Household composition	Alone	28.6%	43.4%	.000
	With spouse only	44.0%	44.8%	.858
	Other	27.4%	11.7%	.000
Respondent status	Alone	12.3%	87.0%	.000
	Proxy	87.7%	13.0%	

(1) NEEDS FOR HUMAN ASSISTANCE WITH ACTIVITIES OF DAILY LIVING FOR ELDERLY WITH AND WITHOUT ADRD



Disentangling shift and share effects

People with ADRD in the sample significantly:

older than people with no ADRD

live less often alone

use more often proxy respondents

Is heterogeneity in the need for care really due to dementia or to the structure induced by the two groups definition ?

Controlling the observable heterogeneity with the Propensity Score Matching (PSM) method

How ?

Sample of elderly aged 75 years and older with ADRD: 513 individuals

Matched with 513 individuals among the 4,165 people with no ADRD

Matching with one-to-one method

Variables used: gender, age, household composition, functional limitations score

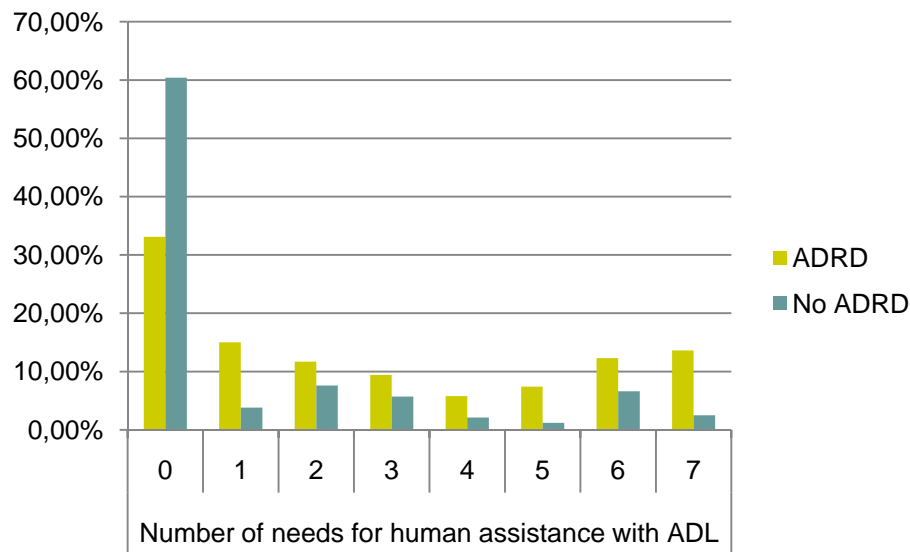
Nearest neighbor method

Sample of 1,026 individuals with no heterogeneity considering socio-demographic characteristics

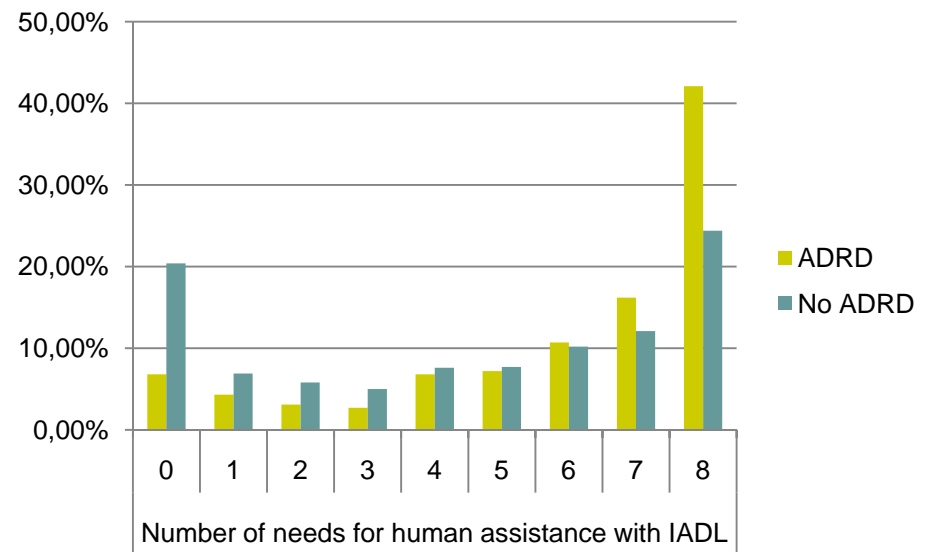
(1) NEEDS FOR HUMAN ASSISTANCE WITH ACTIVITIES OF DAILY LIVING FOR ELDERLY WITH AND WITHOUT ADRD



Distribution of number of needs for human assistance with ADL and IADL, individuals aged 75 years and older with ADRD (n=513) and with no ADRD (n=513), matched samples



P-value for Khi-2 comparison test: <.001



P-value for Khi-2 comparison test: <.001

(1) NEEDS FOR HUMAN ASSISTANCE WITH ACTIVITIES OF DAILY LIVING FOR ELDERLY WITH AND WITHOUT ADRD



Prevalence (%) of need for human assistance with ADL, individuals aged 75 years and older with ADRD (n=513) and with no ADRD (n=513), matched samples

ADL (%)	Elderly with ADRD	Elderly with no ADRD	Matched sample	P-value
Bathing	58.5%	23.0%	40.7%	.000
Dressing	49.5%	19.3%	34.4%	.000
Using toilets	17.7%	3.7%	10.7%	.000
Eating	34.9%	10.9%	22.9%	.000
Transferring from bed or chair	37.4%	13.1%	25.2%	.000
Moving inside	34.1%	13.6%	23.9%	.000
Moving around	63.9%	34.3%	49.1%	.000
At least one ADL	75.2%	39.6%	57.4%	.000

(1) NEEDS FOR HUMAN ASSISTANCE WITH ACTIVITIES OF DAILY LIVING FOR ELDERLY WITH AND WITHOUT ADRD



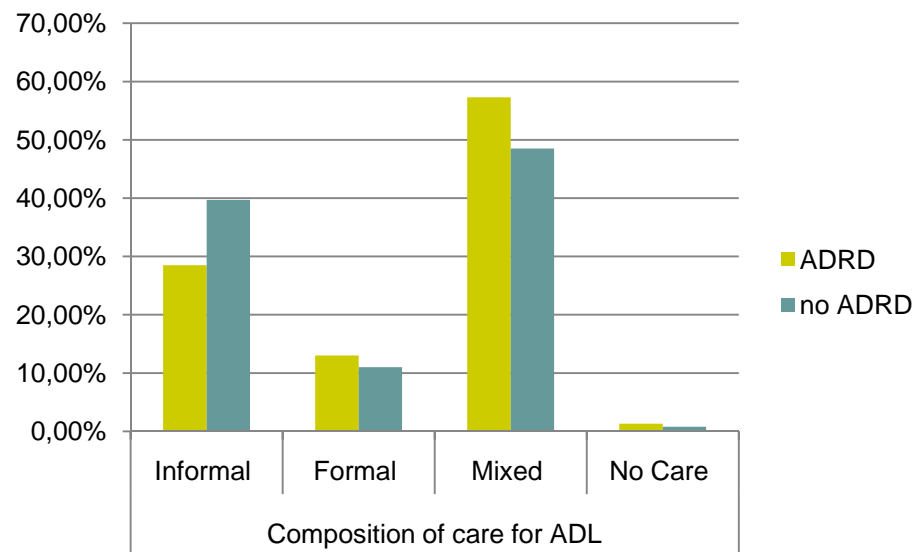
Prevalence (%) of need for human assistance with IADL, individuals aged 75 years and older with ADRD (n=513) and with no ADRD (n=513), matched samples

IADL (%)	Elderly with ADRD	Elderly with no ADRD	Matched sample	P-value
Shopping	84.0%	54.2%	69.1%	.000
Preparing meals	71.9%	31.8%	51.9%	.000
Doing light housework	73.9%	43.3%	58.6%	.000
Doing occasional	78.6%	52.2%	65.4%	.000
Administrative management	83.4%	38.6%	61.0%	.000
Taking medications	67.6%	14.4%	41.0%	.000
Using transports	81.7%	43.9%	62.8%	.000
Using the telephone	55.4%	11.5%	33.4%	.000
At least one IADL	93.2%	66.1%	79.6%	.000

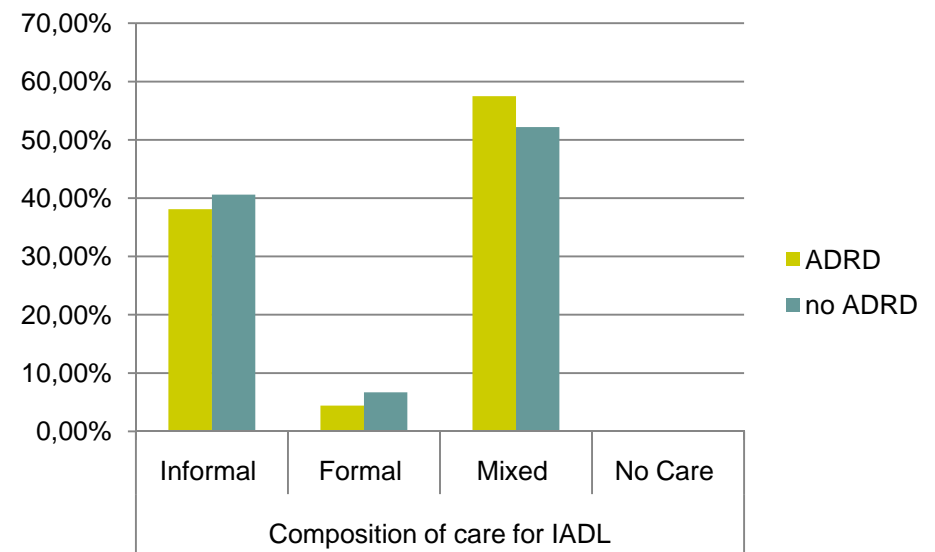
(1) NEEDS FOR HUMAN ASSISTANCE WITH ACTIVITIES OF DAILY LIVING FOR ELDERLY WITH AND WITHOUT ADRD



Composition of care (%) for ADL and IADL, individuals aged 75 years and older with ADRD (n=513) and with no ADRD (n=513), matched samples



P-value for Khi-2 comparison test=.455



P-value for Khi-2 comparison test=.107

(1) NEEDS FOR HUMAN ASSISTANCE WITH ACTIVITIES OF DAILY LIVING FOR ELDERLY WITH AND WITHOUT ADRD



Needs for human assistance with ADLs,
elderly aged 75 years and older with and with no ADRD, matched samples, ZINB model

Variable	Characteristics	P(needs=0)	Count model	Change in expected number of needs
Age	<i>75-79</i>	-	-	-
	<i>80-84</i>	-.012	-.059	-.083
	<i>85-89</i>	.143	-.124#	-.246
	<i>90+</i>	-.452	-.017	.178
Gender	<i>Male</i>	-	-	-
	<i>Female</i>	-.517*	-.060	.168
Household	<i>Alone</i>	-	-	-
	<i>With spouse/companion</i>	-.598*	.219**	.631
	<i>Others</i>	-.611*	.259***	.712
Education	<i>No diploma</i>	.641*	.010	-.292
	<i>Diploma < A-level</i>	.174	.112	.085
	<i>Diploma = A-level</i>	-	-	-
ADRD	<i>Yes</i>	-1.508***	.245***	1.067
	<i>No</i>	-	-	-
Respondent status	<i>Alone</i>	-	-	-
	<i>Helped-replaced</i>	-.962***	.709***	1.386
Physical limitations score		-.370***	.176***	.443
Constant		3.718***	-1.165***	

p-value for the null hypothesis of parameter nullity < .1; * p-value < .05; ** p-value < .01; *** p-value < .001

(1) NEEDS FOR HUMAN ASSISTANCE WITH ACTIVITIES OF DAILY LIVING FOR ELDERLY WITH AND WITHOUT ADRD



Needs for human assistance with IADLs,
elderly aged 75 years and older with and with no ADRD, matched samples, Poisson model

Variable	Characteristics	Parameter	% change in expected number of needs
Age	<i>75-79</i>	-	-
	<i>80-84</i>	-.018	-1.8%
	<i>85-89</i>	.003	.3%
	<i>90+</i>	.135**	14.5%
Gender	<i>Male</i>	-	-
	<i>Female</i>	.077*	8.0%
Household	<i>Alone</i>	-	-
	<i>With spouse/companion</i>	.118**	12.5%
	<i>Others</i>	.163***	17.7%
Education	<i>No diploma</i>	-.012	-1.1%
	<i>Diploma < A-level</i>	.086#	9.0%
	<i>Diploma = A-level</i>	-	-
ADRD	<i>Yes</i>	.468***	59.6%
	<i>No</i>	-	-
Respondent status	<i>Alone</i>	-	-
	<i>Helped-replaced</i>	.632***	88.2%
Physical limitations score		.096***	10.1%
Constant		-.184*	

p-value for the null hypothesis of parameter nullity < .1; * p-value < .05; ** p-value < .01; *** p-value < .001

(2) INFORMAL CARERS OF ELDERLY WITH AND WITH NO ADRD



Sample : 1,335 informal caregivers

Data from the French national survey on informal caregivers (HSA, 2008)

1,335 informal caregivers:

309 caregivers of people with ADRD

1,026 caregivers of people with no ADRD

caring for 1,004 people who need help with daily activities, of whom:

227 are people with ADRD

777 are people with no ADRD

Variables

Socio-demographic characteristics: gender, age, matrimonial status,...

Care hours provided per day and types of care

Consequences of care on health, work, leisure, relationships,...

(2) INFORMAL CARERS OF ELDERLY WITH AND WITH NO ADRD



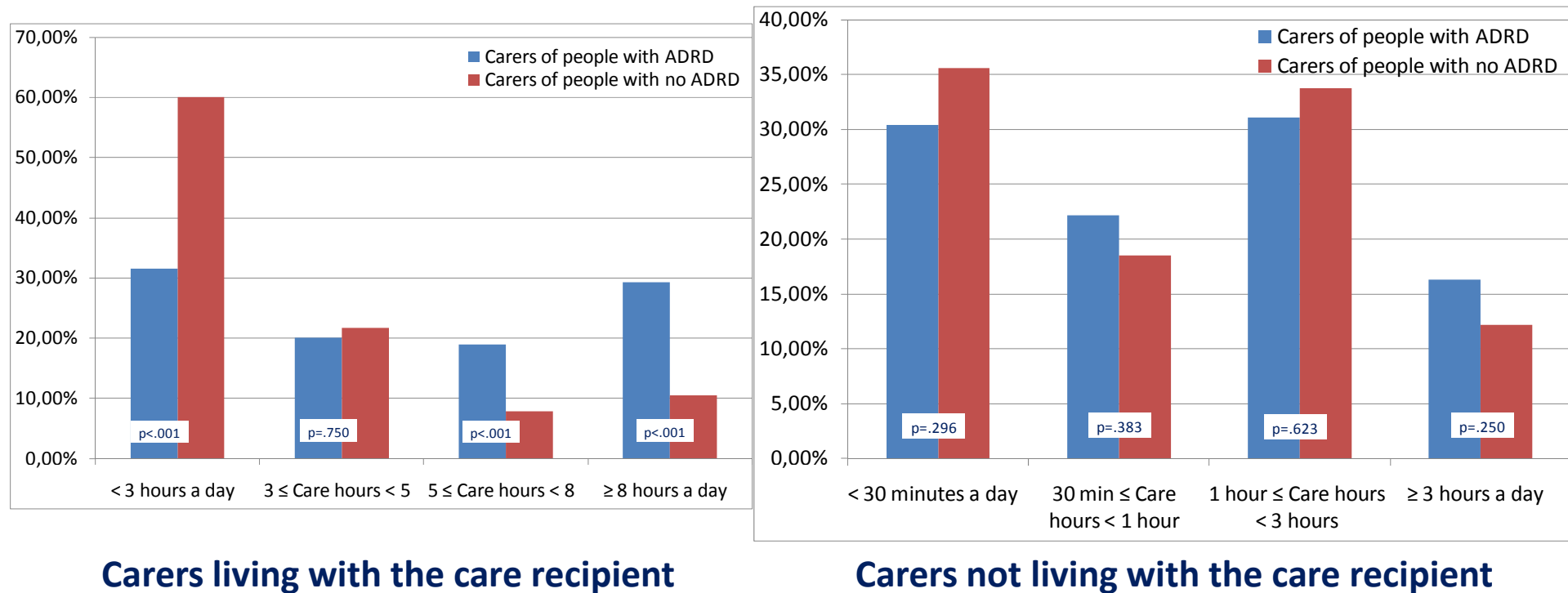
Caregivers characteristics, 309 caregivers of people with ADRD
1,026 caregivers of people with no ADRD

Variable	Characteristics	Carers of people with ADRD	Carers of people with no ADRD	P-value
Gender	Male	37.2%	39.0%	.622
	Female	62.8%	61.0%	
Age	<50	19.4%	22.4%	.242
	50 to 59	30.4%	28.7%	
	60 to 69	16.5%	19.7%	
	70 to 79	20.4%	16.9%	
	80 and older	13.3%	12.4%	
Marital status	Single	18.8%	17.3%	.625
	Married	65.4%	67.6%	.500
	Other	15.9%	15.0%	.785
Occupational status	Employed	37.7%	37.2%	.945
	Part-time work	23.9%	23.2%	.982
In the same house	Yes	56.3%	40.0%	.000
Link with the care recipient	Spouse	27.4%	25.3%	.506
	Children	50.8%	52.4%	.680
	Others	21.8%	22.3%	.894

(2) INFORMAL CARERS OF ELDERLY WITH AND WITH NO ADRD



Care characteristics, care hours



(2) INFORMAL CARERS OF ELDERLY WITH AND WITH NO ADRD



Care characteristics, type of support

Care for:	Carers of people with ADRD	Carers of people with no ADRD	P-value
Medical assistance	90.6%	87.3%	.144
Daily activities	93.5%	91.0%	.204
Company and watch	97.1%	88.6%	.000
Financial support	35.6%	23.4%	.000

Changes in caregivers' family and the social network

Changes in relations with:	Carers of people with ADRD	Carers of people with no ADRD	P-value
Children	18.3%	10.3%	.001
Family	22.6%	15.1%	.003
Friends	24.3%	13.2%	.000

(2) INFORMAL CARERS OF ELDERLY WITH AND WITH NO ADRD



Occupational and social consequences of caregiving

	Carers of people with ADRD	Carers of people with no ADRD	P-value
Work arrangements	26.5%	13.2%	.001
Daily way-outs	52.7%	28.8%	.000
Evening leisure	40.5%	16.9%	.000
Sport activities	22.6%	12.8%	.001
Community life	26.8%	12.4%	.000

(2) INFORMAL CARERS OF ELDERLY WITH AND WITH NO ADRD



Consequences of caregiving on carers' health and healthcare consumption

	Carers of people with ADRD	Carers of people with no ADRD	P-value
Good health	53.7%	59.6%	.039
Poor health	46.3%	40.4%	
Has reported that care affects his/her health	33.3%	17.6%	.000
Has renounced to a medical care for the last 12 months	10.5%	8.9%	.484
Has had no medical examination for the last 12 months	6.8%	9.1%	.261
Takes medication for anxiety and sleep disorders	21.6%	20.8%	.829

(2) INFORMAL CARERS OF ELDERLY WITH AND WITH NO ADRD



Consequences of caregiving on carers' health and healthcare consumption

	Carers of people with ADRD	Carers of people with no ADRD	P-value
Physical tiredness	46.2%	33.2%	.000
Sleep disorders	29.2%	22.7%	.023
Mental tiredness	50.3%	30.0%	.000
Feels alone	42.1%	26.8%	.000
Feels depressive	19.3%	12.1%	.002
Feels anxious, stressed, burn out	44.7%	31.7%	.000
Backaches	39.8%	34.2%	.087
Palpitations, tachycardia	12.2%	12.4%	1.000

CONCLUSION

Assessing the cost of informal care relatively to the cost of formal care

First estimates for the elderly aged 60 years and older

Human assistance reported by care recipients

Informal	11 Billions €
Formal	4.6 Billions €
Total	55.6 Billions €

Human assistance estimated by experts

Informal	7.4 Billions €
Formal	4.9 Billions €
Total	12.3 Billions €

What about the welfare loss?

Constraints on labor market participation

Work arrangements and part-time job

What are caregivers' preferences?

