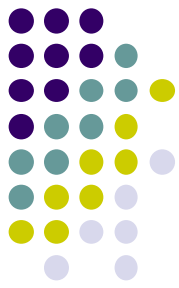


# INFORMAL CARE RECEIVED BY PEOPLE WITH DEMENTIA AGED 75 YEARS AND OLDER

*Empirical evidence from the French National Survey  
on Health and Disability  
'Handicap-Santé Ménages 2008'*

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Bérengère DAVIN



# BACKGROUND

## ● Dementia in the world

- More than 35 million people attained in 2010, with an increase to 65 million in 2030
- From half to two thirds would live in the community *Alzheimer’s Disease International, 2009*

## ● 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*

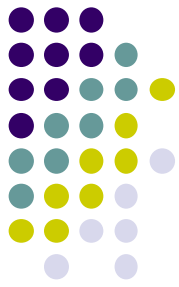
## ● Perspectives

- 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 no dementia aged 75 years and older	850 000	1,300,000	1,800,000

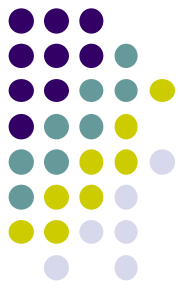
*INSEE, 2010  
Berr, 2010*

- Decrease of the number of informal carers



## OBJECTIVES

- **Comparison (1): people with dementia vs people with no dementia**
  - Socio-demographic characteristics  
(necessity of a *Propensity Score Matching*)
  - Needs for personal assistance with daily activities
  - Types of human assistance (formal / informal / mixed / no care)
  
- **Comparison (2): informal carers of people with dementia vs informal carers of people with no dementia**
  - Socio-demographic characteristics of informal carers
  - Amount of informal care (care hours)
  - Impact of caregiving on carers' life and health



# PEOPLE WITH DEMENTIA / PEOPLE WITH NO DEMENTIA (1)

## ● Sample

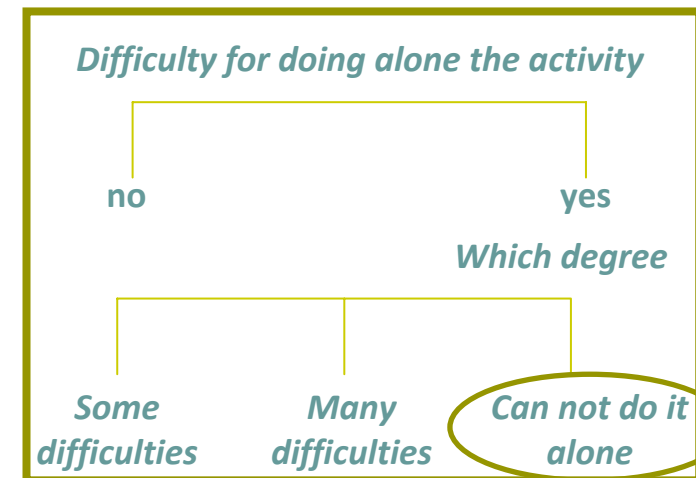
- Data from the French national survey on health and disability (HSM, 2008)
- 4,678 people aged 75 years and older living at home
  - 513 people with dementia
  - 4,165 people with no dementia
- Weighted sample in order to be representative

## ● 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 and 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





No significant difference

# PEOPLE WITH DEMENTIA / PEOPLE WITH NO DEMENTIA (1)

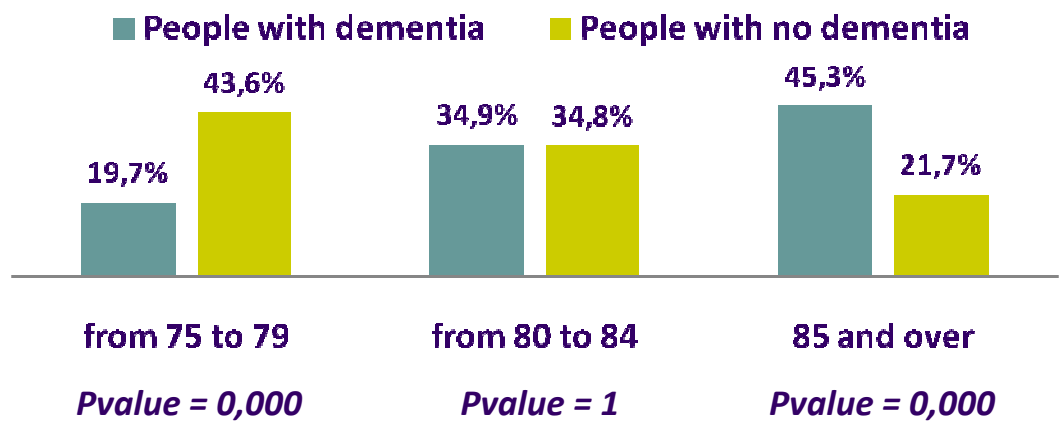
Characteristics – sample of 4,678 individuals – weighted sample

- Gender

	People with dementia	People with no dementia	Pvalue
Men	33,6%	37,6%	0,237
Women	66,4%	62,4%	

- Age

### Age distribution



Significant difference :

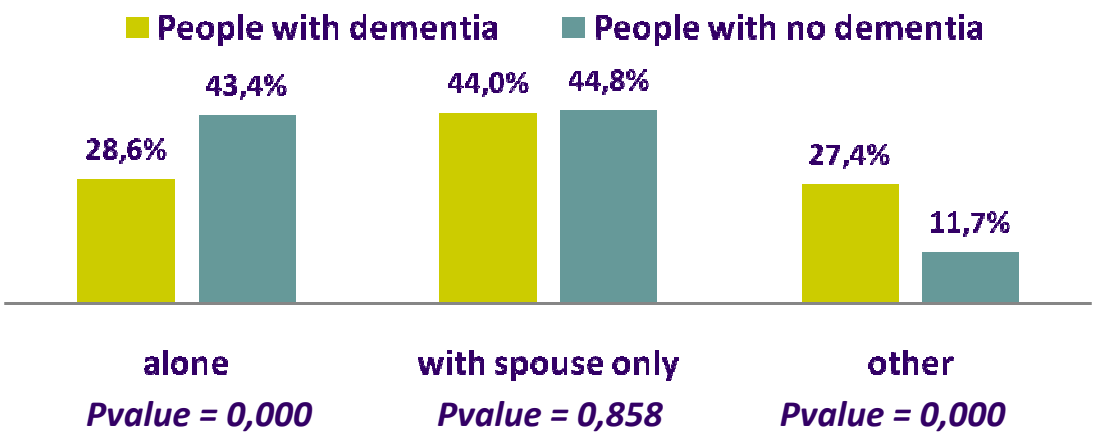
People with dementia are significantly older than people with no dementia



**PEOPLE WITH DEMENTIA / PEOPLE WITH NO DEMENTIA (1)**  
*Characteristics – sample of 4,678 individuals – weighted sample*

- Household**

**Household distribution**

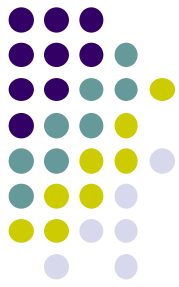


*Significant difference :*  
*People with dementia live significantly less alone than people with no dementia*

- Respondent**

	People with dementia	People with no dementia	Pvalue
Alone	12,3%	87,0%	0,000
Proxy	87,7%	13,0%	

*Significant difference*

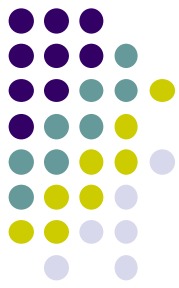


**PEOPLE WITH DEMENTIA / PEOPLE WITH NO DEMENTIA (1)**  
*Need with ADLs – sample of 4,678 individuals – weighted sample*

- ADLs**

ADLs (%)	People with dementia	People with no dementia	Pvalue
Bathing	49,6	4,9	0,000
Dressing	39,5	2,5	0,000
Using toilets	25,5	0,9	0,000
Eating	11,9	0,3	0,000
Transferring from bed or chair	28,9	1,3	0,000
Moving inside	27,3	1,3	0,000
Moving around	53,1	6,6	0,000
<i>At least one ADL</i>	<i>65,3</i>	<i>9,3</i>	<i>0,000</i>

*Significant difference*



**PEOPLE WITH DEMENTIA / PEOPLE WITH NO DEMENTIA (1)**  
*Need with IADLs – sample of 4,678 individuals – weighted sample*

- IADLs**

IADLs (%)	People with dementia	People with no dementia	Pvalue
Shopping	76,2	16,7	0,000
Preparing meals	62,5	5,7	0,000
Doing light housework	64,6	10,9	0,000
Doing occasional housework	72,2	19,1	0,000
Administrative management	79	9,9	0,000
Taking medications	61,5	2,2	0,000
Using transports	72,7	12,9	0,000
Using the telephone	47,1	1,4	0,000
<i>At least one IADL</i>	90,0	26,3	0,000

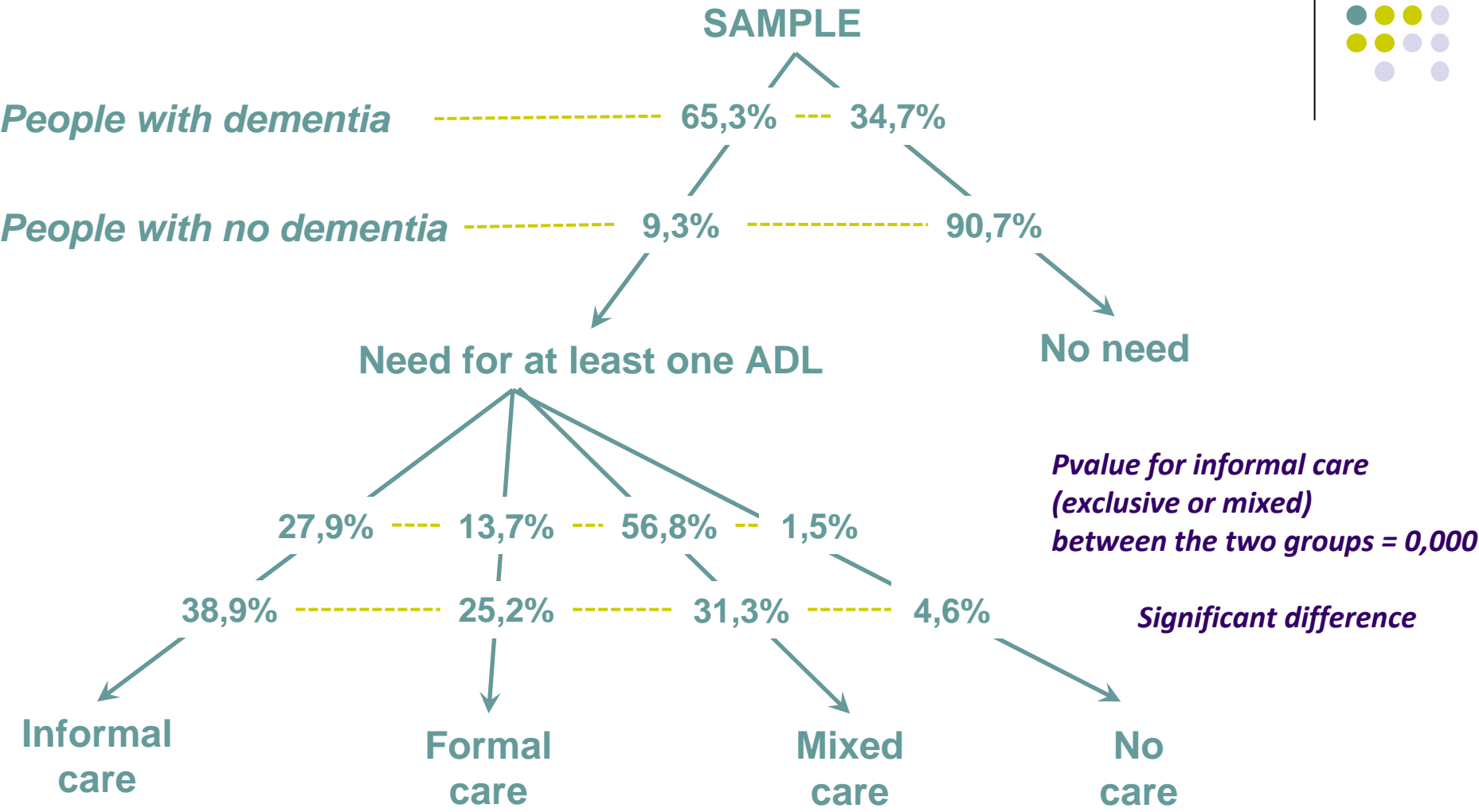
*Significant difference*





# PEOPLE WITH DEMENTIA / PEOPLE WITH NO DEMENTIA (1)

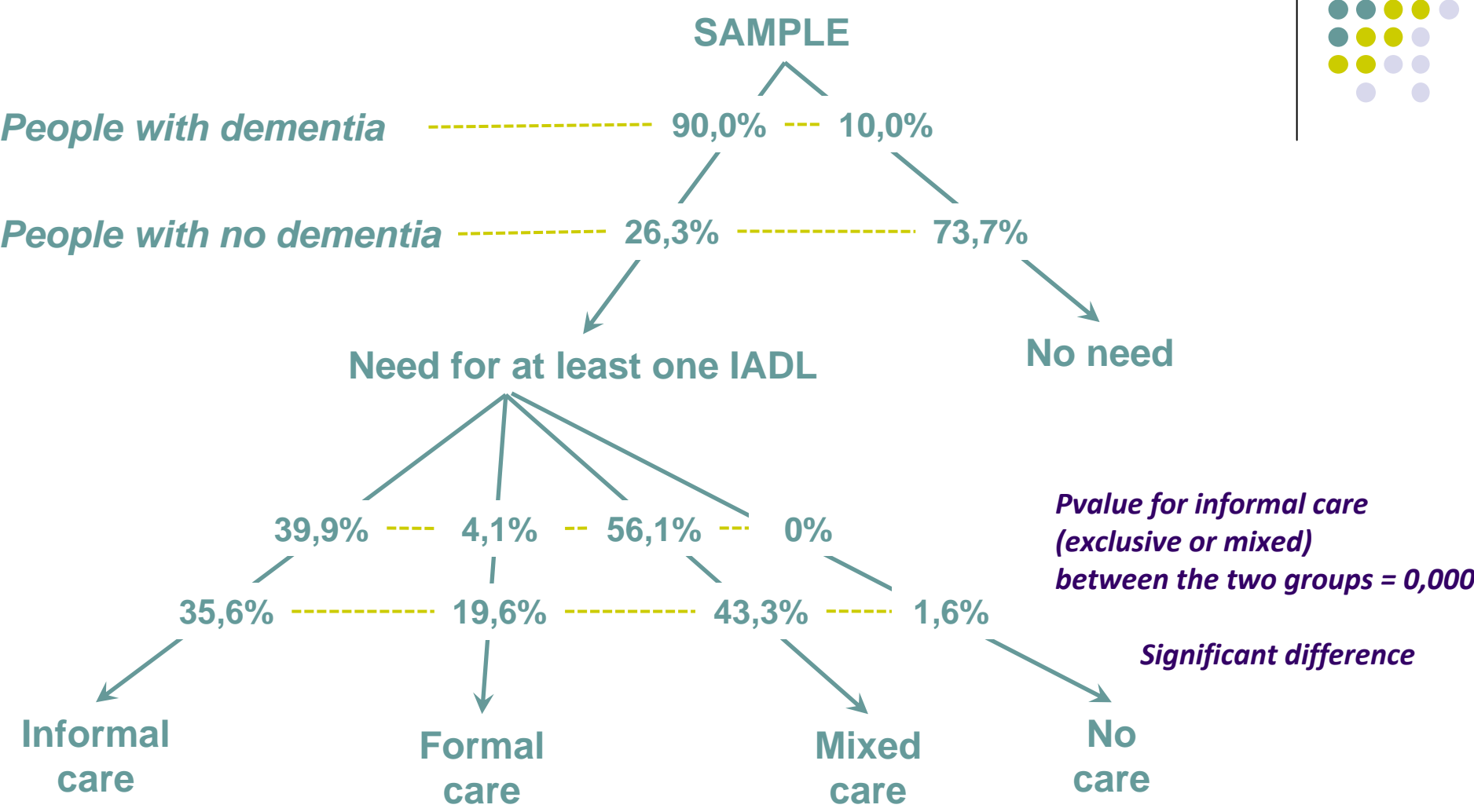
## Type of care with ADLs

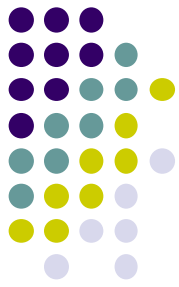




# PEOPLE WITH DEMENTIA / PEOPLE WITH NO DEMENTIA (1)

## Type of care with IADLs





# PEOPLE WITH DEMENTIA / PEOPLE WITH NO DEMENTIA (1)

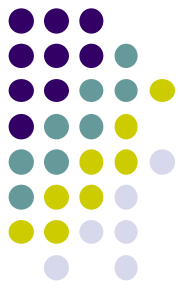
## *Propensity Score Matching*

- **Why ?**

- People with dementia are significantly older than people with no dementia in our sample, they live less alone, and more proxy respondents have been required for them
- Is heterogeneity for need and care really due to dementia or to the structure induced by the two groups definition ?
- The Propensity Score Matching permits control of the observable heterogeneity

- **How ?**

- The current sample contains data for 513 people with dementia
- These 513 people with dementia are matched to 513 individuals among the 4,165 people with no dementia
- Matching one-to-one method in order to get a sample of 1,026 individuals showing no heterogeneity as regards to socio-demographic characteristics



# PEOPLE WITH DEMENTIA / PEOPLE WITH NO DEMENTIA (1)

## Propensity Score Matching : covariate balances

- Age

	Before Matching	After Matching (redressed weights)
mean - dementia	84,2	84,2
mean - no dementia	81,3	84,1
var ratio (Tr/Co)	1,205	0,767
T-test p-value	<b>0,000</b> <i>Significant difference</i>	<b>0,731</b> <i>No more significant difference</i>

- Household (alone)

	Before Matching	After Matching (redressed weights)
% - dementia	26,9%	28,6%
% - no dementia	43,2%	30,4%
var ratio (Tr/Co)	0,802	0,964
T-test p-value	<b>0,000</b> <i>Significant difference</i>	<b>0,617</b> <i>No more significant difference</i>



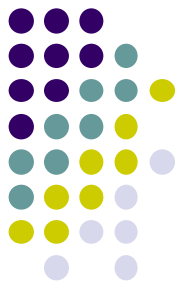
# PEOPLE WITH DEMENTIA / PEOPLE WITH NO DEMENTIA (1)

## Need with ADLs – PSM – unweighted sample

- ADLs

ADLs (%)	People with dementia	People with no dementia	Pvalue
Bathing	58,5	27,3	0,000
Dressing	49,5	23,6	0,000
Using toilets	34,9	14,0	0,000
Eating	17,7	3,5	0,000
Transferring from bed or chair	37,4	15,4	0,000
Moving inside	34,1	15,6	0,000
Moving around	63,9	38,6	0,000
<i>At least one ADL</i>	75,2	46,2	0,000

*Difference diminished but still significant*



# PEOPLE WITH DEMENTIA / PEOPLE WITH NO DEMENTIA (1)

## Need with IADLs – PSM – unweighted sample

- IADLs

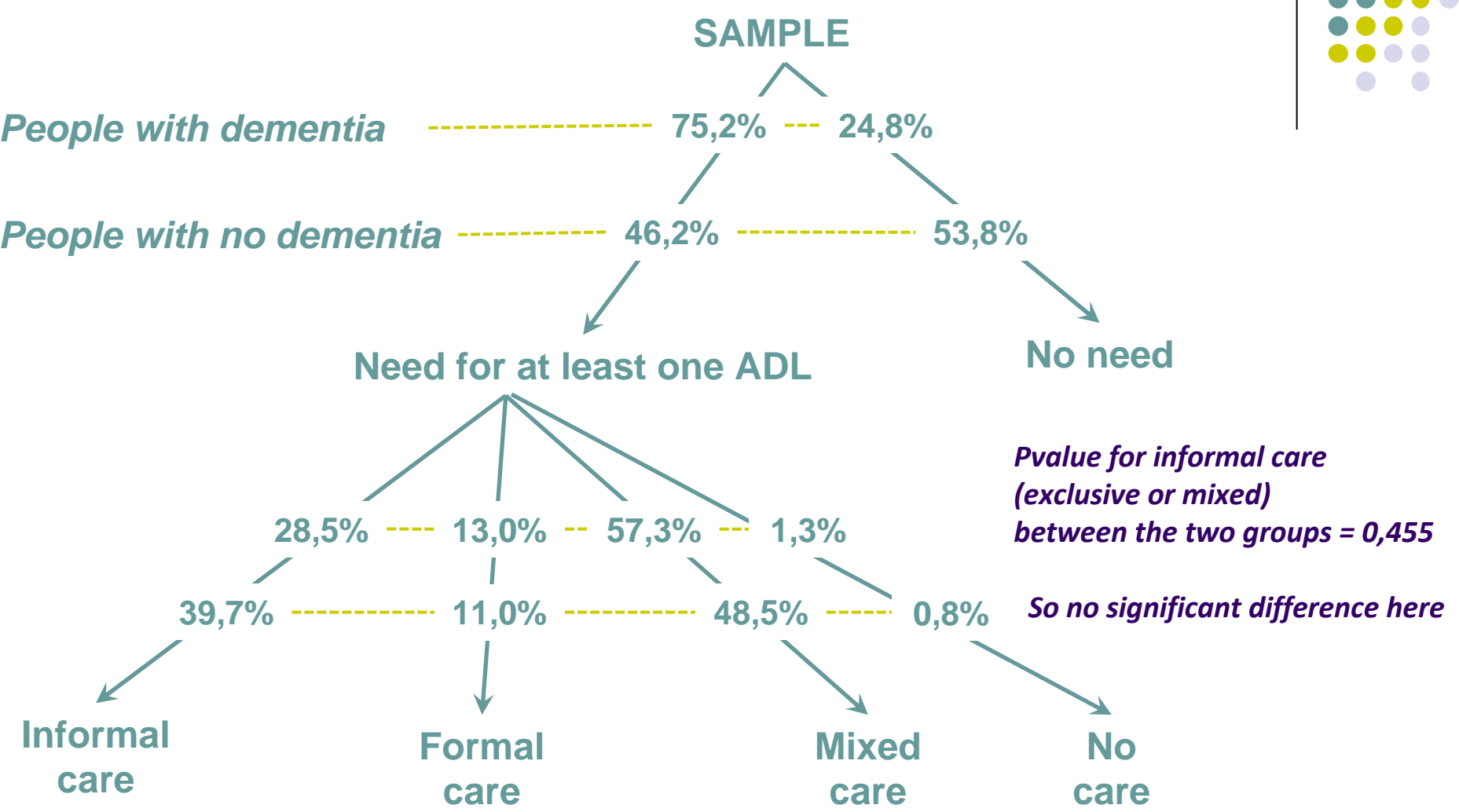
IADLs (%)	People with dementia	People with no dementia	Pvalue
Shopping	84,0	60,2	0,000
Preparing meals	71,9	36,6	0,000
Doing light housework	73,9	47,2	0,000
Doing occasional housework	78,6	56,7	0,000
Administrative management	83,4	48,1	0,000
Taking medications	67,6	18,7	0,000
Using transports	81,7	50,5	0,000
Using the telephone	55,4	14,0	0,000
<i>At least one IADL</i>	93,2	70,2	0,000

*Difference diminished but still significant*



# PEOPLE WITH DEMENTIA / PEOPLE WITH NO DEMENTIA (1)

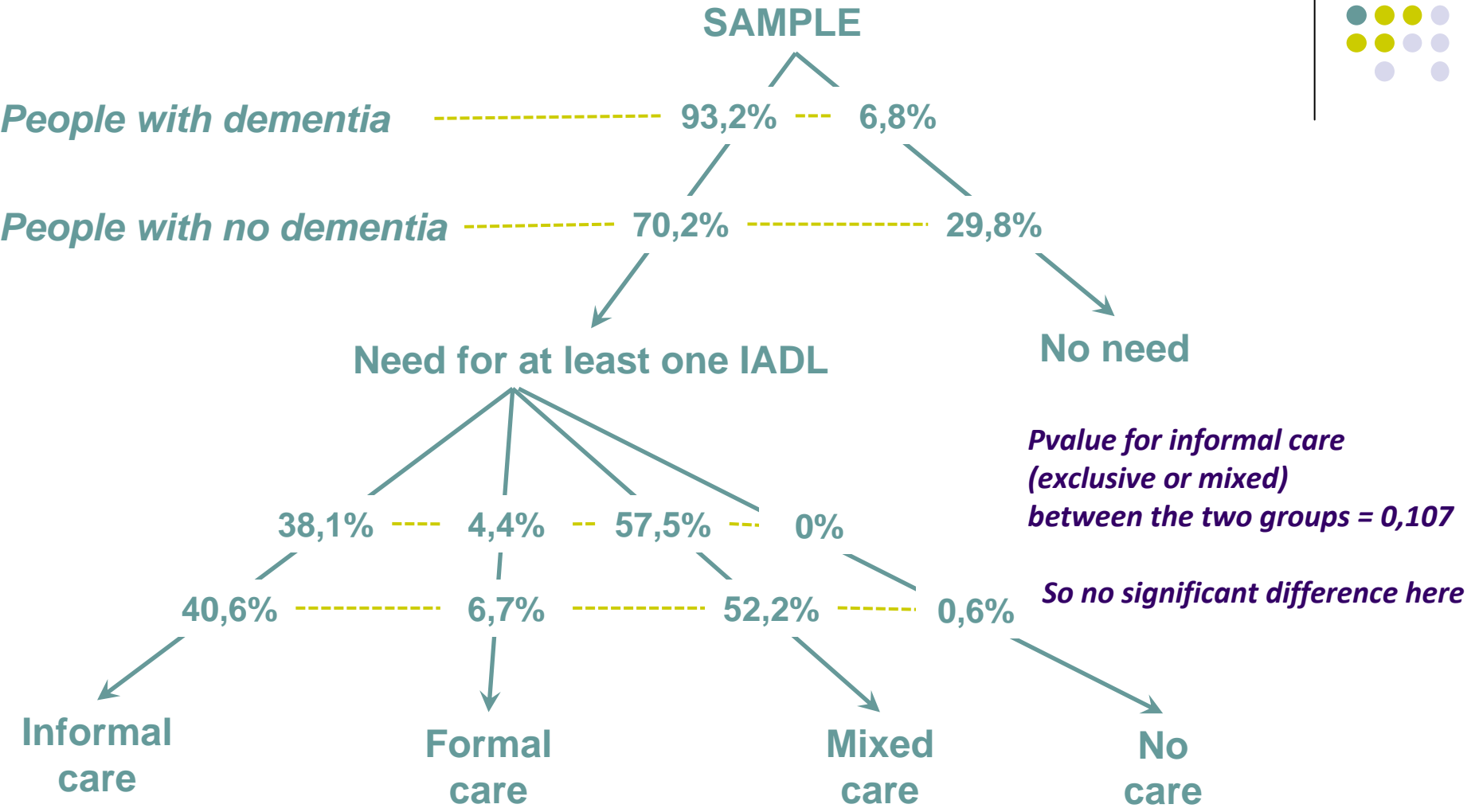
Type of care with ADLs – PSM – unweighted sample



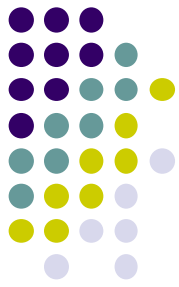


# PEOPLE WITH DEMENTIA / PEOPLE WITH NO DEMENTIA (1)

Type of care with IADLs – PSM – unweighted sample







## INFORMAL CARERS OF PEOPLE WITH AND WITHOUT DEMENTIA (2)

- **Sample : 1,335 informal carers**
  - Data from the French national survey on informal caregivers (HSA, 2008)
  - 1,335 informal caregivers:
    - 309 caregivers of people with dementia
    - 1,026 carers of people with no dementia
  - They are caring for 1,004 people who need help with daily activities, of whom 227 are people with dementia
- **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...



# INFORMAL CARERS OF PEOPLE WITH AND WITHOUT DEMENTIA (2)

## Characteristics of the sample

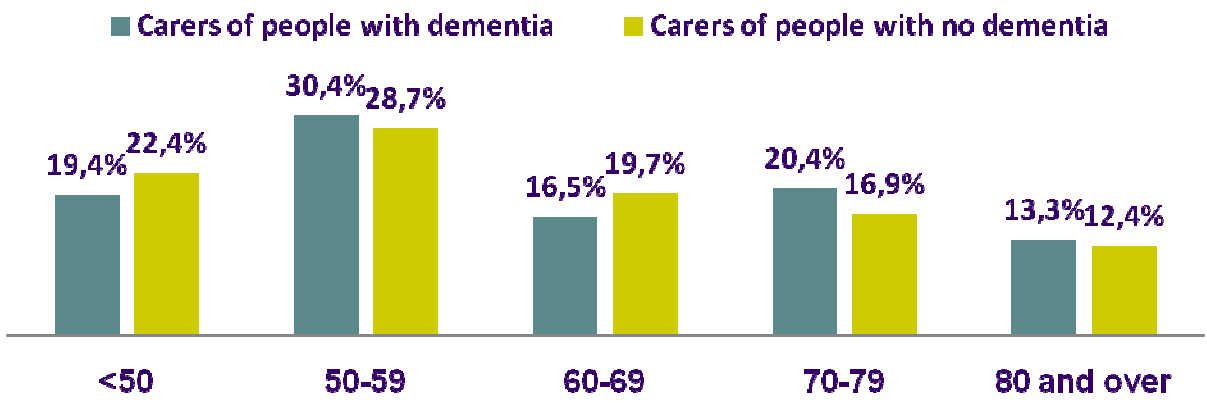
- Gender

	Carers of people with dementia	Carers of people with no dementia	Pvalue
Men	37,2%	39,0%	0,622
Women	62,8%	61,0%	

No significant difference

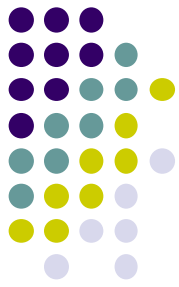
- Age

### Age distribution



Mean 1 = 61,7  
 Mean 2 = 60,6  
 Pvalue = 0,242

No significant difference



# INFORMAL CARERS OF PEOPLE WITH AND WITHOUT DEMENTIA (2)

## Characteristics of the sample

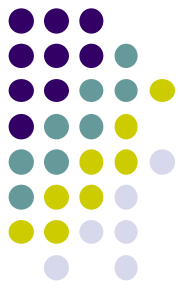
	Modality	Carers of people with dementia	Carers of people with no dementia	Pvalue
Matrimonial status	Single	18,8%	17,3%	0,625
	Married	65,4%	67,6%	0,500
	Other	15,9%	15,0%	0,785
Work	Employed	37,7%	37,2%	0,945
Among the workers	Part-time work	23,9%	23,2%	0,982
Relationship between the carer and the person who needs help	Spouses	27,4%	25,3%	0,506
	Children	50,8%	52,4%	0,680
	Others	21,8%	22,3%	0,894
Living in the same house	Yes	56,3%	40,0%	0,000

*No significant difference*

*Significant difference*



Almost 40% of children who help people with dementia live with their relatives, compared to 20% of children who help people with no dementia.



# INFORMAL CARERS OF PEOPLE WITH AND WITHOUT DEMENTIA (2)

## Characteristics of care – Care hours

- Carers who live with the person who needs assistance

	Carers of people with dementia	Carers of people with no dementia	Pvalue
< 3 hours a day	31,6%	60,0%	0,000
3 ≤ Care hours < 5	20,1%	21,7%	0,750
5 ≤ Care hours < 8	19,0%	7,8%	0,000
≥ 8 hours a day	29,3%	10,5%	0,000

*Significant difference*

- Carers who do not live with the person who needs assistance

	Carers of people with dementia	Carers of people with no dementia	Pvalue
< 30 minutes a day	30,4%	35,6%	0,296
30 min ≤ Care hours < 1 hour	22,2%	18,5%	0,383
1 hour ≤ Care hours < 3 hours	31,1%	33,8%	0,623
≥ 3 hours a day	16,3%	12,2%	0,250

*No significant difference*



# INFORMAL CARERS OF PEOPLE WITH AND WITHOUT DEMENTIA (2)

## Characteristics of care – Type of support

Care for...	Carers of people with dementia	Carers of people with no dementia	Pvalue
Medical assistance	90,6%	87,3%	0,144
Daily activities	93,5%	91,0%	0,204
Company and watch	97,1%	88,6%	0,000
Financial support	35,6%	23,4%	0,000

*No significant difference*

*Significant difference*



# INFORMAL CARERS OF PEOPLE WITH AND WITHOUT DEMENTIA (2)

## Consequences of care – Relationships

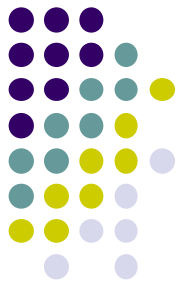
- Relationship with children

	Carers of people with dementia	Carers of people with no dementia	Pvalue
The carer has observed changes	18,3%	10,3%	0,001

*Significant difference*



	Carers of people with dementia	Carers of people with no dementia	Pvalue
Relationship has been degraded	48,7%	38,2%	0,375



*Significant difference*

*Significant difference*

# INFORMAL CARERS OF PEOPLE WITH AND WITHOUT DEMENTIA (2)

## Consequences of care – Relationships

- Relationship with family

	Carers of people with dementia	Carers of people with no dementia	Pvalue
The carer has observed changes	22,6%	15,1%	0,003



	Carers of people with dementia	Carers of people with no dementia	Pvalue
Relationship has been degraded	66,1%	57,2%	0,299

- Relationship with friends

	Carers of people with dementia	Carers of people with no dementia	Pvalue
The carer has observed changes	24,3%	13,2%	0,000



	Carers of people with dementia	Carers of people with no dementia	Pvalue
Relationship has been degraded	87,5%	82,1%	0,458



*Significant difference*

*Significant difference*

# INFORMAL CARERS OF PEOPLE WITH AND WITHOUT DEMENTIA (2)

## Consequences of care – Professional and social life

- Impact on carers' career (among workers)

	Carers of people with dementia	Carers of people with no dementia	Pvalue
Work arrangements	26,5%	13,2%	0,001

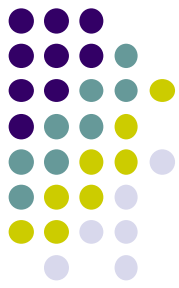


	Carers of people with dementia	Carers of people with no dementia	Pvalue
Reducing/rescheduling working hours	73,3%	78,0%	0,839

- Impact on carers' social life (among those concerned)

Impact on...	Carers of people with dementia	Carers of people with no dementia	Pvalue
Daily way-outs	52,7%	28,8%	0,000
Evening leisure	40,5%	16,9%	0,000
Sport activities	22,6%	12,8%	0,001
Community life	26,8%	12,4%	0,000





# INFORMAL CARERS OF PEOPLE WITH AND WITHOUT DEMENTIA (2)

## Consequences of care – Impact on health

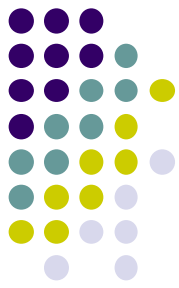
The carer...	Carers of people with dementia	Carers of people with no dementia	Pvalue
Has renounced to a medical care for the last 12 months	10,5%	8,9%	0,484
Has had no medical examination for the last 12 months	6,8%	9,1%	0,261
Takes medication for anxiety and sleep disorders	21,6%	20,8%	0,829
Has reported that care affects his/her health	33,3%	17,6%	<b>0,000</b>

*Significant difference*



Reported health	Carers of people with dementia	Carers of people with no dementia	Pvalue
Good health	53,7%	59,6%	<b>0,039</b>
Poor health	46,3%	40,4%	

*Significant difference*



# CONCLUSION

- **Needs and assistance due to dementia**

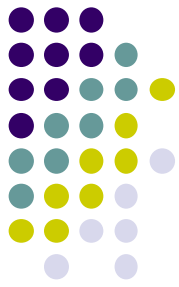
- 65% of aged people with dementia need assistance for ADLs and 90% for IADLs, which is significantly more than for aged people with no dementia
- More than 85% of people with dementia receive informal care for daily activities, which is not significantly more than for aged people with no dementia

- **Impact of dementia on informal carers**

- Among carers who live with their relatives, caregivers of people with dementia spend significantly more time giving care (50% spend at least 5 hours a day caring)
- One out of five carers of people with dementia reports that his/her relationships have been changed (more often degraded), which is significantly more than for other carers
- A quarter of working carers of people with dementia have made work arrangements and a majority have left aside their social life, which shows a significant difference with other carers
- A third of carers of people with dementia report that care affects their health, which is significantly more than other carers

- **Prospects**

- Necessity for developing a fitted coverage on the medical and sociomedical scope in order to support caregivers and their demented relatives
- Working carers ought to benefit from legal and compensated arrangements of working conditions
- Recognition of informal care and additional financial support to help families to face the costs of dementia



*Thank you for your attention*