



52° CONGRESSO NAZIONALE SIGG
Firenze, 28 novembre- 2 dicembre 2007

**... e c'è bisogno anche della
relazione con il PAZIENTE
FAMIGLIA**

The fine art of patient-doctor relationships

M P Park, R H R Park **BMJ** VOLUME 329 18-25 DECEMBER 2004 bmj.com

Orazio ZANETTI

Società Italiana di Gerontologia e Geriatria
U.O. Alzheimer - Centro per la Memoria
IRCCS, Centro S.Giovanni di Dio - Fatebenefratelli,
Brescia



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Fig 1 Goya's *Self Portrait with Dr Arrieta*, 1820. Minneapolis Institute of Arts, The Ethel Morrison Derlip Fund

**Oggi in Italia meno del 2% (1.96%)
degli >65enni sono
ospiti/ricoverati in strutture
residenziali (n. 223.509) e meno
dell'1% sono seguiti a domicilio.
(In Europa: 5% in residenze e 7%
al domicilio)**

(Fonte: Istat 2004; C.Gori e A.Guaita: I luoghi della cura 2007)

IRCCS Centro S.Giovanni di Dio-Fatebenefratelli, Brescia



**Oggi in Italia l' 80% circa dei
pazienti affetti da demenza è
assistita al proprio domicilio dalla
famiglia, spesso con il supporto di
“badanti”**

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I nodi della rete

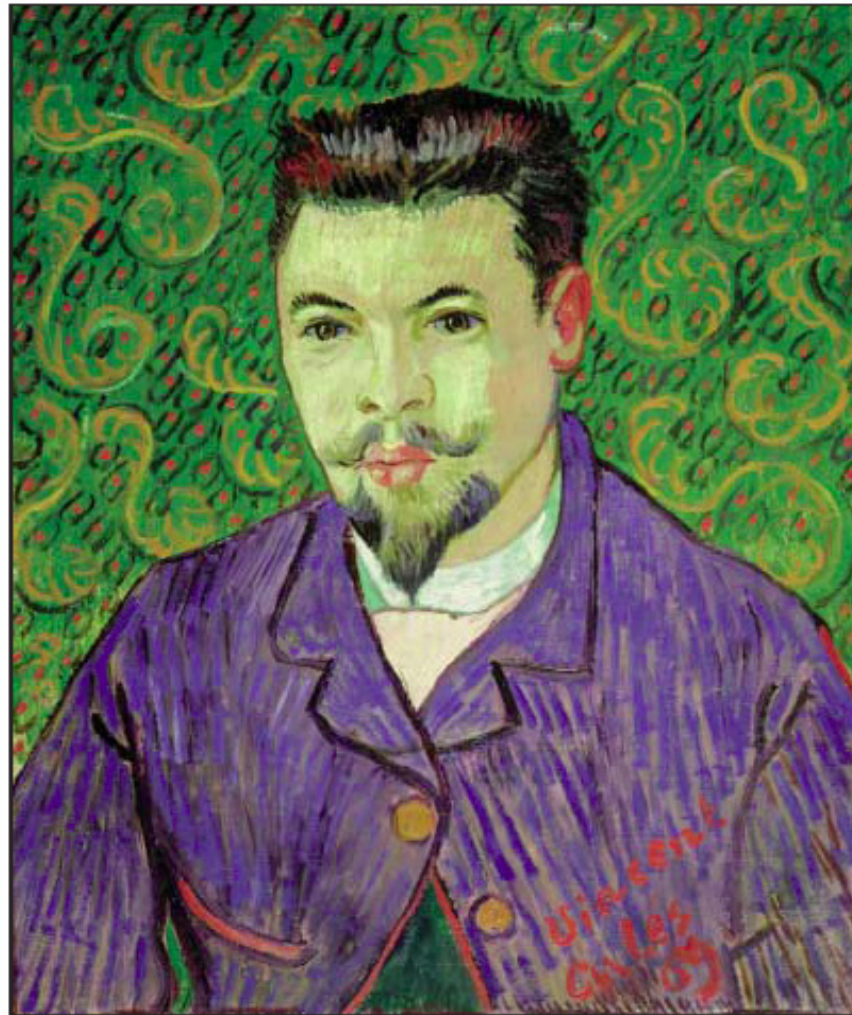
- **Caregiver ("badanti")- paziente**
- **Medico di famiglia**
- **ADI**
- **RSA - Unità Alzheimer (SCU)**
- **Centro Diurno Integrato (CDI)**
- **Unità Operative di Degenza e Day Hospital**
- **U.V.A.**



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BRIDGEMAN ART LIBRARY

Fig 3 Van Gogh's *Portrait of Félix Rey*, 1889. Pushkin Museum, Moscow



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**... c'è bisogno anche della
relazione con il paziente ...**



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Fig 2 Bellany's *Bonjour Professor Calne*, 1988. Aberdeen Art Gallery and Museums Collections

Il paziente nella fase diagnostica

*“Sono un medico degli anziani, perchè è venuto da me?”
(Come posso esserle utile? Cosa posso fare per lei?)”*

“ ? ... Mi hanno portato loro ... ”

“Sig.ra Bianchi mi dica come sta? Lei come si sente?”

“Io sto bene!”

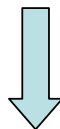


Il paziente nella fase diagnostica

“l’ appetito?”, **“buono !”**; *“digerisce bene?”*,
“abbastanza”; *“ha dolori?”* **“si ho questo
ginocchio ...”**; *“e la memoria, come va?”*
**“sa dottore, alla mia età non si può
pretendere”**; *“Sig.ra Bianchi, quanti anni ha?”*
“ ... Sono del ’27”



CONSAPEVOLEZZA, INSIGHT, AWARENESS, COSCIENZA



DEPRESSIONE - SOFFERENZA

COMPETENZA - CONSENSO

COMPLIANCE - OUTCOME

CAREGIVER BURDEN

ASPETTI ETICI E MEDICO LEGALI

*(testamento, direttive anticipate - living wills -
testamento di vita)*





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Il paziente nella fase diagnostica

Lo spazio per l'empatia



The fine art of patient-doctor relationships

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BMJ VOLUME 329 18-25 DECEMBER 2004 bmj.com



BRIDGEMAN ART LIBRARY

Fig 4 Van Gogh's *L'Homme à la Pipe, Dr Gachet*, 1890. Bibliothèque Nationale Paris



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Il paziente e la restituzione della diagnosi



■ Position Paper

W Research criteria for the diagnosis of Alzheimer's disease: revising the NINCDS-ADRDA criteria

Bruno Dubois, Howard H Feldman*, Claudia Jacova, Steven T DeKosky, Pascale Barberger-Gateau, Jeffrey Cummings, André Delacourte, Douglas Galasko, Serge Gauthier, Gregory Jicha, Kenichi Meguro, John O'Brien, Florence Pasquier, Philippe Robert, Martin Rossor, Steven Salloway, Yaakov Stern, Pieter J Visser, Philip Scheltens*

Lancet Neurol 2007; 6: 734–46

Published Online

July 9, 2007

DOI:10.1016/S1474-

4422(07)70178-3

August 2007

Panel 2: Diagnostic criteria for AD

Probable AD: A plus one or more supportive features B, C, D, or E

Core diagnostic criteria

1 A. Presence of an early and significant episodic memory impairment that includes the following features:

1. Gradual and progressive change in memory function reported by patients or informants over more than 6 months
2. Objective evidence of significantly impaired episodic memory on testing: this generally consists of recall deficit that does not improve significantly or does not normalise with cueing or recognition testing and after effective encoding of information has been previously controlled
3. The episodic memory impairment can be isolated or associated with other cognitive changes at the onset of AD or as AD advances

Supportive features

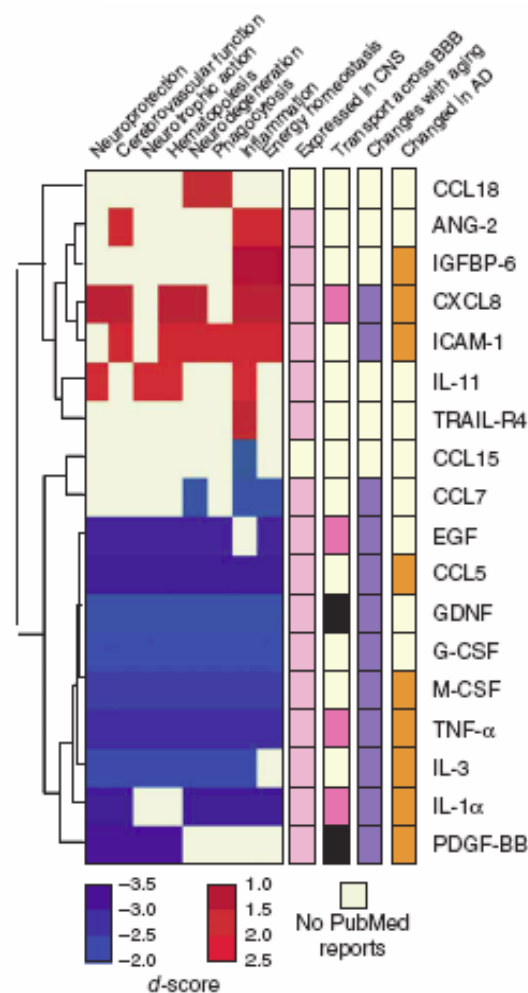
- 2 B. Presence of medial temporal lobe atrophy
- Volume loss of hippocampi, entorhinal cortex, amygdala evidenced on MRI with qualitative ratings using visual scoring (referenced to well characterised population with age norms) or quantitative volumetry of regions of interest (referenced to well characterised population with age norms)
- 3 C. Abnormal cerebrospinal fluid biomarker
- Low amyloid β_{1-42} concentrations, increased total tau concentrations, or increased phospho-tau concentrations, or combinations of the three
 - Other well validated markers to be discovered in the future
- 4 D. Specific pattern on functional neuroimaging with PET
- Reduced glucose metabolism in bilateral temporal parietal regions
 - Other well validated ligands, including those that foreseeably will emerge such as Pittsburgh compound B or FDDNP
- E. Proven AD autosomal dominant mutation within the immediate family

Classification and prediction of clinical Alzheimer's diagnosis based on plasma signaling proteins

Sandip Ray^{1,16}, Markus Britschgi^{2,16}, Charles Herbert¹, Yoshiko Takeda-Uchimura², Adam Boxer³, Kaj Blennow⁴, Leah F Friedman⁵, Douglas R Galasko⁶, Marek Jutel⁷, Anna Karydas³, Jeffrey A Kaye⁸, Jerzy Leszek⁹, Bruce L Miller⁵, Lennart Minthon¹⁰, Joseph F Quinn⁸, Gil D Rabinovici⁵, William H Robinson¹¹, Marwan N Sabbagh¹², Yuen T So², D Larry Sparks¹², Massimo Tabaton¹³, Jared Tinklenberg⁵, Jerome A Yesavage⁵, Robert Tibshirani¹⁴ & Tony Wyss-Coray^{2,15}

Received 2 May; accepted 30 August; published online 14 October 2007; doi:10.1038/nm1653

A molecular test for Alzheimer's disease could lead to better treatment and therapies. We found 18 signaling proteins in blood plasma that can be used to classify blinded samples from Alzheimer's and control subjects with close to 90% accuracy and to identify patients who had mild cognitive impairment that progressed to Alzheimer's disease 2–6 years later. Biological analysis of the 18 proteins points to systemic dysregulation of hematopoiesis, immune responses, apoptosis and neuronal support in presymptomatic Alzheimer's disease.



INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY

Int J Geriatr Psychiatry 2004; **19**: 151–169.

Published online in Wiley InterScience (www.interscience.wiley.com). DOI: 10.1002/gps.1050

Disclosing a diagnosis of dementia: a systematic review

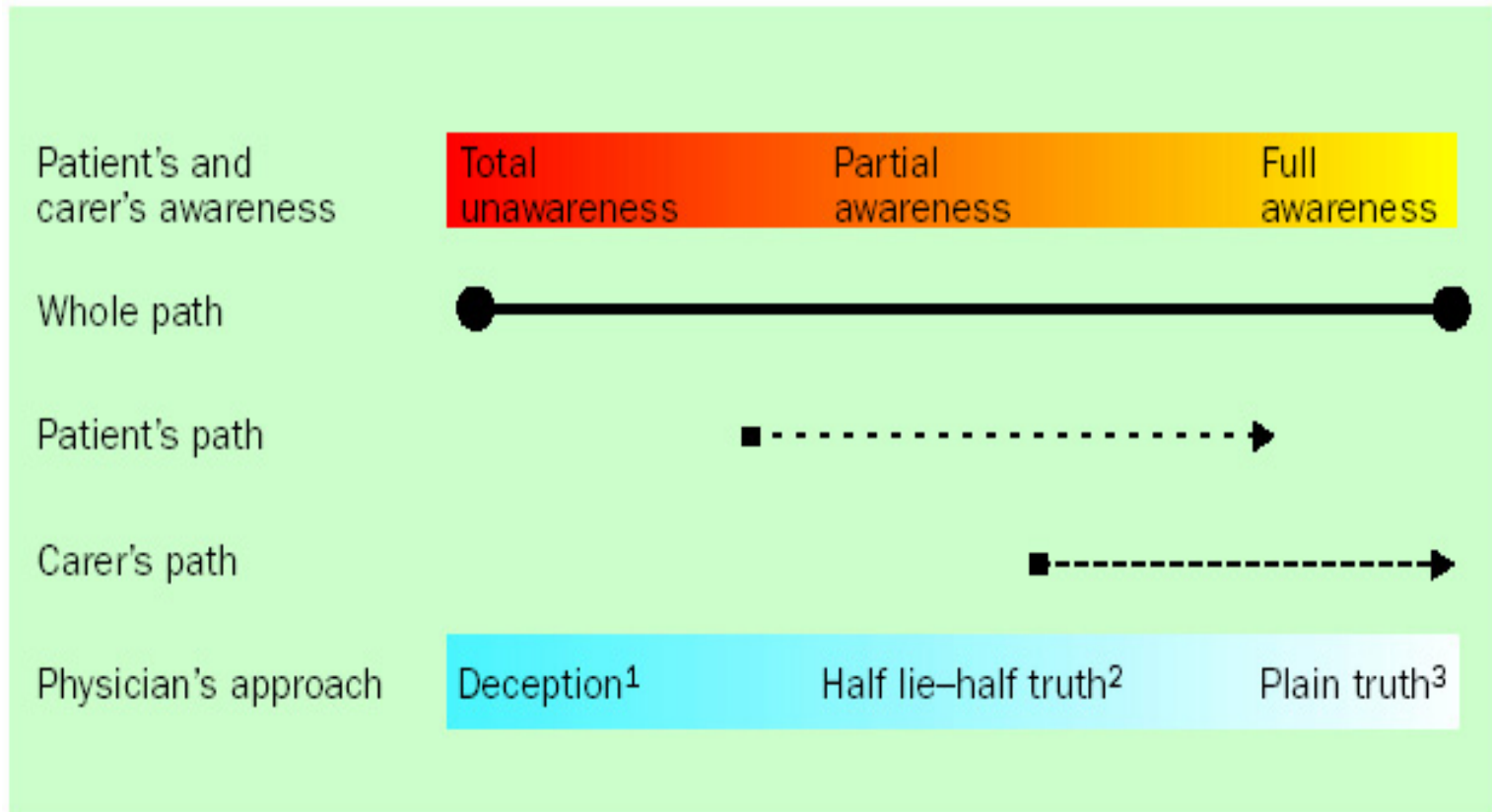
Claire Bamford, Sharon Lamont, Martin Eccles*, Louise Robinson, Carl May and John Bond

Centre for Health Services Research, University of Newcastle-upon-Tyne, UK

Studies of the impact of disclosure indicate both negative and positive consequences of diagnostic disclosure for people with dementia and their carers.

Conclusions Existing evidence regarding diagnostic disclosure in dementia is both inconsistent and limited with the perspectives of people with dementia being largely neglected. This state of knowledge seems at variance with current guidance about disclosure. Copyright © 2004 John Wiley & Sons, Ltd.





Frisoni GB: Lancet Neurology 2004



Handwritten signature or initials in blue ink, appearing to be 'G.F.O.'

The fine art of patient-doctor relationships

MP Park, R HR Park **BMJ** VOLUME 329 18-25 DECEMBER 2004 bmj.com



Munch's *Portrait of Dr Jacobsen*, 1909. Munch Museum, Oslo



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Il paziente nella fase della restituzione della diagnosi

***“Sig. Bianchi, fino al prossimo
controllo Le consiglio di non guidare
l’automobile”***





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Il paziente nella fase della restituzione della diagnosi

***Il paziente, il coniuge, gli altri familiari,
necessitano di informazioni qualitativamente
e quantitativamente diverse***

***Cura orientata alla famiglia (oltre che al paziente), come nel
modello pediatrico***





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**... e c'è bisogno anche della
relazione con la famiglia**





Michelangelo, *La Sacra Famiglia (Tondo Doni)*, circa 1503 Olio e tempera su tavola, Firenze, Uffizi



Pietro Antonio Longhi (Venezia, 1701-1785) , Famiglia Patrizia



Roberto Guarneri



Pompeo Girolamo Batoni (Lucca, 1708 - Roma, 1787)

Zarit S.H., Reever K.E., and
Bach-Peterson J.: Relatives of
the impaired elderly:
correlates of feeling of burden.

The Gerontologist 1980; 20: 260-266

Council report (AMA)

Physicians and Family Caregivers

A Model for Partnership

JAMA 1993; 269; 1282 1284.

... family caregivers, key resources for the frail elderly.

.... family members play a central and essential role in the health care and care management of the community-dwelling , frail elderly



Council report (AMA)

Physicians and Family Caregivers

A Model for Partnership

JAMA 1993; 269; 1282 1284.

**... family support reduce health care
utilization by the elderly .. Informal
support may retard institutionalization**

...

IRCCS Centro S.Giovanni di Dio-Fatebenefratelli, Brescia



Council report (AMA)

Physicians and Family Caregivers

A Model for Partnership

JAMA 1993; 269; 1282 1284.

Caregivers and patients as a single unit of care and caregiver as a partner with the physician in care of the patient

IRCCS Centro S.Giovanni di Dio-Fatebenefratelli, Brescia



Council report (AMA)

Physicians and Family Caregivers

A Model for Partnership

JAMA 1993; 269; 1282 1284.

- **Patient caregiver unit**
- **Comprehensive home-based approach**
- **Caregiver and patient assessment**
- **Providing training to caregiver**
- **Offer specific help for upsetting behaviors**
- **Validate the caregiver role**
- **Act as case manager**

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I famigliari fonte di informazioni

- esordio ed evoluzione dei deficit cognitivi**
- disturbi comportamentali**
- comparsa dei deficit funzionali**



Associazione tra report del caregiver e valutazione diretta

ELEVATA : *PERFORMANCE* MOTORIA (deambulazione)

MODERATA-BUONA : VESTIRSI

MODERATA: USO DEL TELEFONO, GESTIONE
FINANZE, FARE LA SPESA

NO ASSOCIATION: TOILETTE

LE DISCREPANZE TRA CAREGIVER *REPORT* E MISURE
DI *PERFORMANCE* DIRETTA SONO
SIGNIFICATIVAMENTE INFLUENZATE DAL CAREGIVER
BURDEN

Zanetti et al.: J. Am. Geriatr. Soc. 1999;47:196 202.





52° CONGRESSO NAZIONALE SIGG
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I famigliari come target di cure

Il carico fisico e psicologico della famiglia, del *caregiver* primario in particolare



DETERMINANTS OF BURDEN IN AN ITALIAN SAMPLE OF ALZHEIMER'S PATIENT CAREGIVERS

The **greater the number of persons**, the lower the report of caregiver stress.

Lower frequency of visits of friends or relatives, caregiver's poor health and higher age, and the presence of patient's behavioural disturbances were the main determinants of caregiver's depressive symptoms.

Cognitive impairment of patients was not correlated to caregiver's distress.

Zanetti et al., J.Cross-Cultural Gerontology, 1996



INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY

Int J Geriatr Psychiatry 2005; **20**: 168–174.

Published online in Wiley InterScience (www.interscience.wiley.com). DOI: 10.1002/gps.1267

Predictors of high level of burden and distress in caregivers of demented patients: results of an Italian multicenter study

P. Rinaldi¹, L. Spazzafumo², R. Mastroforti¹, P. Mattioli¹, M. Marvardi¹, M. C. Polidori¹, A. Cherubini, G. Abate³, L. Bartorelli⁴, S. Bonaiuto⁵, A. Capurso⁶, D. Cucinotta⁷, M. Gallucci⁸, M. Giordano⁹, M. Martorelli¹⁰, G. Masaraki¹¹, A. Nieddu¹², C. Pettenati¹³, P. Putzu¹⁴, V. A. Tammaro¹⁵, P. F. Tomassini¹⁶, C. Vergani¹⁷, U. Senin¹, P. Mecocci^{1*} and the Study Group on Brain Aging of the Italian Society of Gerontology and Geriatrics (GSIC-SIGG)

Predictors of high level of burden and distress in caregivers of demented patients: results of an Italian multicenter study

P. Rinaldi¹, L. Spazzafano², R. Manfredi³, P. Manti⁴, M. Mariani⁵, M. C. Polidori¹, A. Cherubini⁶, G. Alzate⁷, L. Bartorelli⁸, S. Bonaiuto⁹, A. Capurso⁸, D. Cuccinotta¹, M. Gallucci⁸, M. Giordano⁸, M. Martelli¹⁰, G. Masaraki¹¹, A. Nreddo¹², C. Petrucci¹³, P. Pizzi¹⁴, V. A. Tarrao¹⁵, P. F. Tomassini¹⁶, C. Vergani¹⁷, U. Senin¹⁸, P. Mecocci¹⁹ and the Study Group on Brain Aging of the Italian Society of Gerontology and Geriatrics (SIGG-SKGG)

Table 4. Multivariate analysis of patient's and caregiver's variables associated to the risk of belonging to the high burden, distress, depression and anxiety (HBDDA) group

	OR	CI 95%
ADL		
Mild disability (5–6)	1	
Moderate disability (3–4)	4.01	1.87–8.61
Severe disability (0–2)	6.55	3.28–13.30
NPI agitation		
None	1	
Mild (1–4)	1.09	0.55–2.16
Moderate (5–8)	3.41	1.42–8.22
Severe (9–12)	3.86	1.38–10.81
NPI irritability		
None	1	
Mild (1–4)	1.15	0.57–2.28
Moderate (5–8)	2.99	1.27–7.05
Severe (9–12)	2.58	0.78–8.49
NPI aberrant motor behaviour		
None	1	
Mild (1–4)	1.73	0.77–3.91
Moderate (5–8)	3.19	1.43–7.08
Severe (9–12)	2.60	1.04–6.46
NPI night time behaviours		
None	1	
Mild (1–4)	2.11	1.05–4.25
Moderate (5–8)	2.75	1.30–5.85
Severe (9–12)	3.27	1.09–9.77
Caregiver's age		
≤ 50 years	1	
51–69 years	2.07	0.96–4.45
≥ 70 years	3.40	1.29–8.98
Type of relationship		
Others	1	
Child	5.02	1.96–12.85
Spouse	6.70	2.27–19.12
Place of living		
North	1	
Center	0.91	0.44–1.87
South	2.98	1.38–6.44

ENTE OSPEDALIERO PROV. GAVARDO - BALDO
OSPEDALE DI GAVARDO

DIVISIONE MEDICA
PEDIATRO PROF. ANTONIO FERRARINI

Gavardo _____



dall'ospedale di Gavardo

o. Garofalo

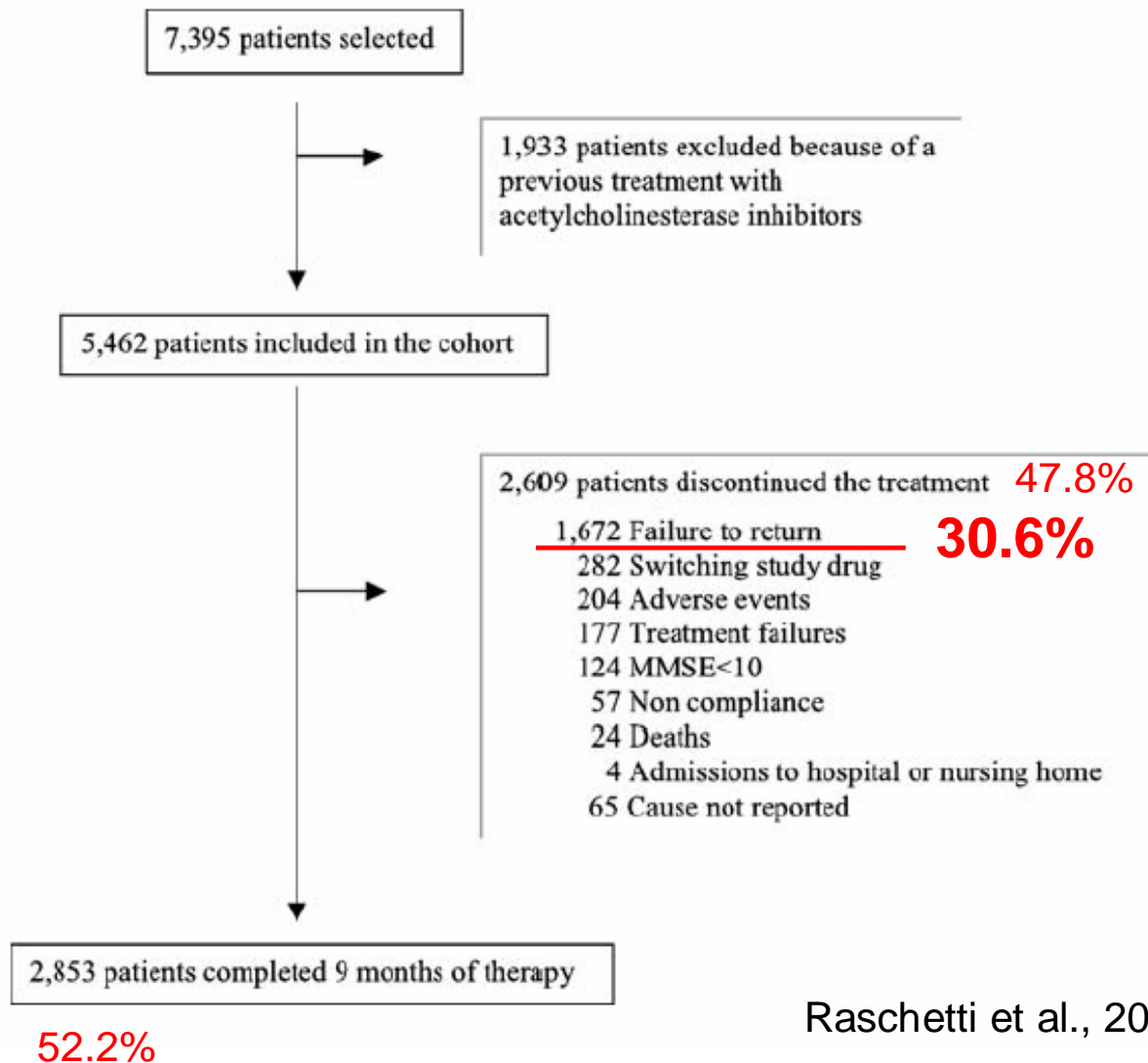
1980

Eur J Clin Pharmacol (2005) 61: 361–368
DOI 10.1007/s00228-005-0946-1

CLINICAL TRIALS

Roberto Raschetti · Marina Maggini
Giacoma Carla Sorrentino · Nello Martini
Bruno Caffari · Nicola Vanacore

**A cohort study of effectiveness of acetylcholinesterase inhibitors
in Alzheimer's disease**



FUNZIONI UVA

Diagnosi etiologica del deficit cognitivo
Interventi farmacologici e non farmacologici
(riabilitazione cognitiva e fisica)
Gestione dei disturbi comportamentali
Diagnosi e terapia della comorbidità
Prevenzione
Educazione e supporto dei familiari
**Interazione con gli altri nodi della rete dei
servizi per l'anziano con deficit cognitivi**
Formazione (*Ricerca e formazione*)

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M P Park, R H R Park

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EDINBURGH ART LIBRARY

Fig 7 Dad's Portrait of Sir Alexander Morison, 1852, Scottish National Portrait Gallery, Edinburgh

Meta-Analysis of Psychosocial Interventions for Caregivers of People with Dementia

*Henry Brodaty, MD, FRANZCP, FRACP, *† Alisa Green, B. Sc (Psychol). Hons,†
and Annette Koschera, PhD†*

J Am Geriatr Soc 51:657–664, 2003

Table 3. Effect Size for Psychological Morbidity at Most Current Follow-Up Assessment

Study	Standardized Mean Difference ^a (95% Confidence Interval)
Moniz-Cook et al. 1998 (GHQ)	1.81 (0.94–2.67)
Marriot et al. 2000 (GHQ)	1.57 (0.69–2.45)
Hinchliffe et al. 1995 (GHQ)	1.42 (0.64–2.21)
Teri et al. 1997; problem solving (HDRS)	1.10 (0.27–1.92)
Quayhagen et al. 1989 (HSC)	0.92 (–0.16–2.00)
Brodaty and Gresham 1989 (GHQ)	0.77 (0.27–1.28)
Quayhagen et al. 2000; cog. stimulation (BSI)	0.59 (–0.09–1.27)
Teri et al. 1997; pleasant events (HDRS)	0.53 (–0.23–1.29)
Zanetti et al. 1998 (BSI)	0.46 (–0.42–1.34)
Chang et al. 1999 (BSI)	0.45 (–0.04–0.95)
Mittelman et al. 1995 (GDS)	0.29 (0.02–0.60)
Mohide et al. 1990 (CES-D)	0.26 (–0.36–0.87)
Ostwald et al. 1999 (CES-D)	0.25 (–0.20–0.70)
McCurry et al. 1998 (CES-D)	0.21 (–0.58–1.00)
Hebert et al. 1994 (BSI)	0.20 (–0.47–0.86)
Ripich et al. 1998 (PANAS)	0.15 (–0.50–0.81)
Quayhagen et al. 2000; day care (BSI)	0.12 (–0.58–0.83)
Kahan et al. 1985 (SDS)	0.09 (–0.53–0.72)
Gendron et al. 1996 (HSC)	0.07 (–0.60–0.73)
Zarit et al. 1987; counseling (BSI)	0.02 (–0.43–0.48)
Morris et al. 1992 (BDI)	–0.09 (–0.80–0.63)
Brodaty et al. 1994 (GHQ)	–0.16 (–0.71–0.38)
Zarit et al. 1987; support group (BSI)	–0.17 (–0.60–0.27)
Logiudice et al. 1999 (GHQ)	–0.18 (–0.87–0.52)
Roberts et al. 1999 (PAIS)	–0.24 (–0.75–0.28)
Quayhagen et al. 2000; dyadic counseling (BSI)	–0.59 (–1.23–0.05)

INTERVENTIONS FOR CAREGIVERS OF PATIENTS WITH DEMENTIA

SUPPORT GROUPS

INDIVIDUAL AND FAMILY COUNSELLING

RESPIRE CARE

SKILLS TRAINING INTERVENTIONS

**COMPREHENSIVE, MULTI-COMPONENT
INTERVENTIONS**



Bob
8-9-85
Peters

RESEARCH LETTER

'Immigrant paid caregivers' and primary caregivers' burden

E. Rosa¹*, M. Ambrogio², G. Binetti² and O. Zanetti²

¹AFAR, Research Association Fatebenefratelli, Rome, Italy

²Alzheimer's Research and Care Unit-Memory Clinic—IRCCS—Centro S. Giovanni di Dio-Fatebenefratelli Brescia, Italy

Table 1. Association between objective and subjective caregiver burden with the availability of an immigrant paid caregiver

Subjective and Objective burden	Immigrant paid caregiver			
	No (n = 33) M (DS)	Yes (n = 18) M (DS)	f	Sig.
<i>H. dedicate to vigilance</i>	15.79 (9.4)	5.00 (6.4)	18.70	0.000*
<i>H. dedicated to assistance</i>	3.06 (2.7)	1.00 (1.3)	8.91	0.004*
CBI*				
<i>Time dependence burden</i>	14.15 (6.4)	7.61 (4.3)	14.68	0.000*
<i>Developmental burden</i>	8.00 (5.8)	4.39 (5.7)	5.73	0.021*
<i>Physical burden</i>	7.91 (4.8)	4.61 (4.3)	4.51	0.039*
<i>Social burden</i>	4.97 (4.7)	6.06 (5.5)	5.74	0.466
<i>Emotional burden</i>	3.88 (3.3)	1.83 (1.8)	0.54	0.020*
CES-D**	26.00 (13.7)	15.39 (14.5)	6.66	0.013*

*Caregiver Burden Inventory.

**CES-D: Center for Epidemiological Studies Depression Scale.

La vita riposta:

i costi sociali ed economici della malattia di Alzheimer

P. Spadin e C.M. Vaccaro

Franco Angeli, Milano, 2007

	1999	2006
Assistenza diretta (ore/d)	7.0	6.0
Sorveglianza (ore/d)	10.8	7.0

The immigrant paid caregivers' role in the care of patients with severe dementia

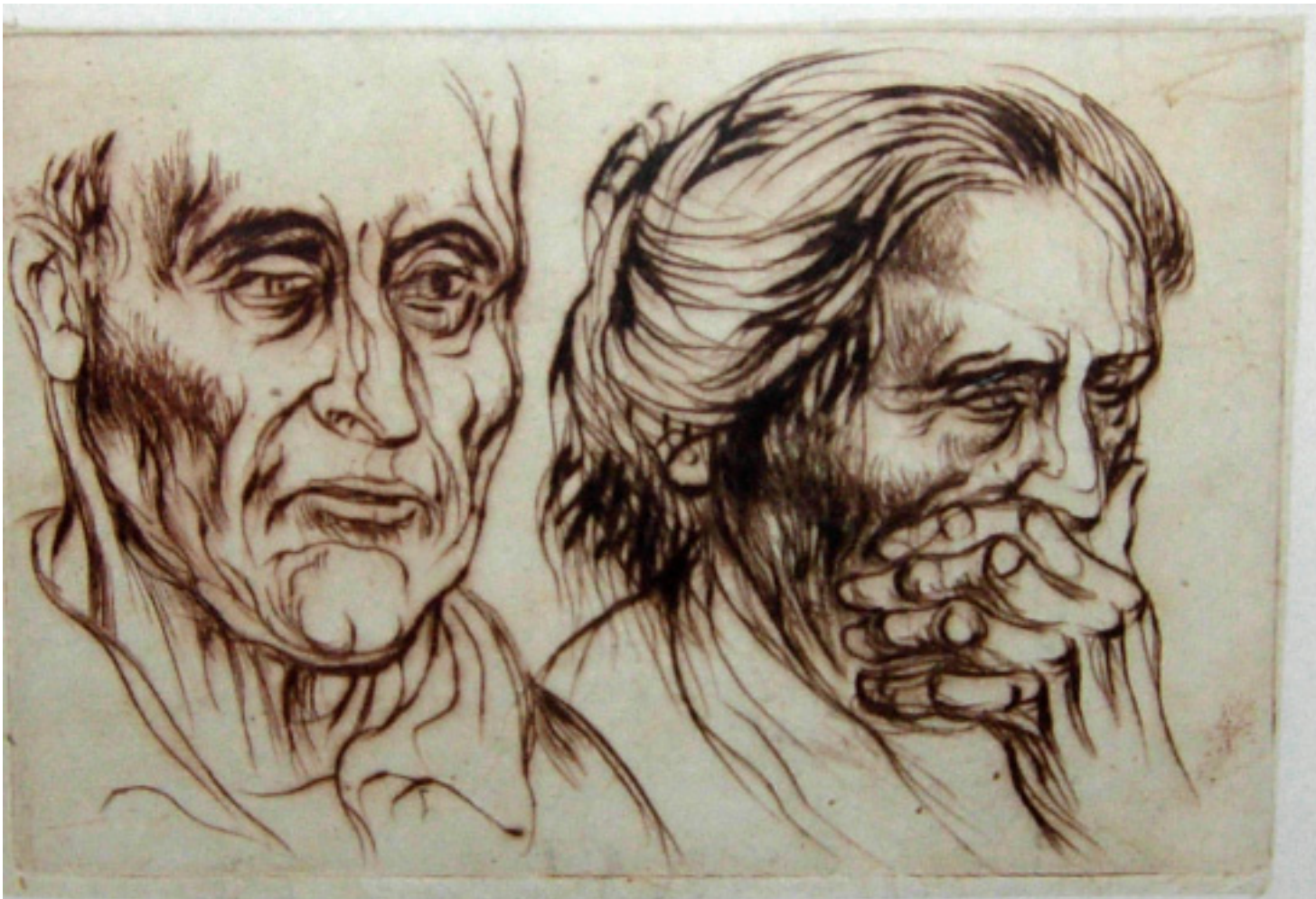
E. Rosa*, G. Lussignoli, F. Sabbatini, A. Chiappa, S. Di Cesare, L. Lamanna, B. Surreante and O. Zanetti

Alzheimer's Research and Care Unit, Memory Clinic, IRCCS-Centro S. Giovanni di Dio, Fabbrospertini Brescia, Italy

Badanti:n.50

	Mean SD	N	%
<i>Age</i>	41 ± 10		
<i>Sex</i>			
Female		49	98
Male		1	2
<i>Education</i>	13 ± 2		
8 years		6	12
13 years		28	56
more than 13 years		16	32
<i>Language</i>			
Fairly good Italian		18	36
Good Italian		17	34
Very good Italian		15	30
<i>Civil status</i>			
Married		37	74
Single		3	6
Divorced		7	14
Widower/Widow		3	6

<i>Relationship with the patient</i>		
Good	33	66
Not very good	17	34
<i>Relationship with the caregiver</i>		
Good	31	62
Not very good	19	38
<i>Illegal work in Italy</i>		
Yes	33	66
No	17	34
<i>First experience as immigrant paid caregiver</i>		
Yes	26	52
No	24	48
<i>Training to care for patients</i>		
Yes	6	12
No	44	86
<i>Need of a specific training to care for a patient with dementia</i>		
Yes	40	80
No	10	20
<i>Economic situation</i>		
Good	22	44
Not good	28	56
<i>Depressive symptoms (CES-D)</i>		
Absence	30	66
Mild	10	17
Severe	10	17
<i>Hours of vigilance</i>	13 ± 6	
<i>Hours of assistance</i>	2 ± 1	



P.D.A 2/5

A. Hayashi '28





BMJ | 17 NOVEMBER 2007 | VOLUME 335

Respecting the subjective: quality measurement from the patient's perspective

An unhappy patient suggests poor quality care, but **Glyn Elwyn and colleagues** point out that using measures of satisfaction to assess health providers is not without problems