

PROBLEMATIQUES ETHIQUES DANS LA PRISE EN CHARGE DES PERSONNES ATTEINTES D'UNE PATHOLOGIE DEMENTIELLE



Pierluigi Quadri
 Servizio Sottocenerino di Geriatria
 Ospedali regionali di Lugano e Mendrisio
 pierluigi.quadri@eoc.ch

Les démences: le poids du problème

OFS, 2012




CH 2015: 115'000; 40% aide quotien
 30% assistance 24/24h


2030: 190'000; 2060: 300'000

Dementia

Clinical Presentation




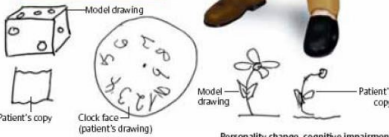
WIKIPÉDIA
L'encyclopédie libre



Loss of cognitive function

- Memory impairment (Short- and long-term memory)
- Impairment of other higher cortical functions (abstraction, judgment, arithmetic, aphasia, apraxia, agnosia, attention)
- Personality change
- Loss of social and occupational skills





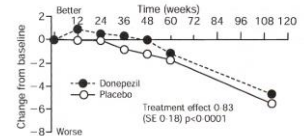
Personality change, cognitive impairment

La démence ...

... est une sérieuse perte ou une réduction des capacités cognitives suffisamment importante pour retentir sur la vie d'un individu et entraîner une perte d'autonomie. Les fonctions cérébrales particulièrement atteintes peuvent être la mémoire, l'attention, et le langage ...

... Elle atteint la personnalité en ce qui concerne le fait d'être raisonnable", c'est-à-dire dans le système de ses valeurs logiques, de connaissance, de jugement et d'adaptation au milieu social ...

... au caractère de déchéance progressive, incurable

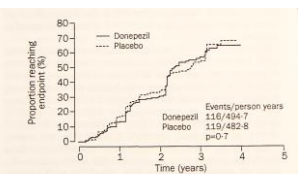


Change in MMSE (upper) and effect of donepezil (lower)

Time (weeks)	Donepezil	Placebo
0	0	0
12	0.2	-0.2
24	0.4	-0.4
36	0.6	-0.6
48	0.8	-0.8
60	1.0	-1.0
72	1.2	-1.2
84	1.4	-1.4
96	1.6	-1.6
108	1.8	-1.8
120	2.0	-2.0

Treatment effect 0.83 (SE 0.18) p<0.0001

Time (weeks)	Donepezil	Placebo
0	281	282
12	245	263
24	211	229
36	185	192
48	165	168
60	154	160
120	94	87



Events/person years: Donepezil 119/484-7, Placebo 119/482-8, p=0-7

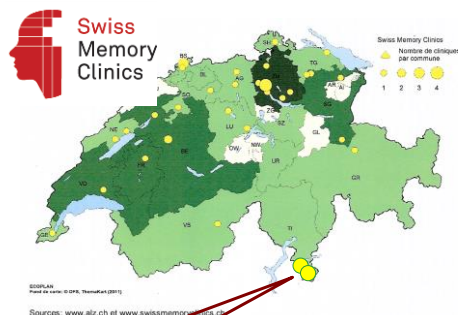
Time (years)	Donepezil	Placebo
0	281	282
1	203	199
2	126	122
3	45	50
4	1	0

- *DIGIS Evaluable*
- *Rogers, 1996+2000*
- *Winblad, 2000*
- *Tettamanti, 2006*

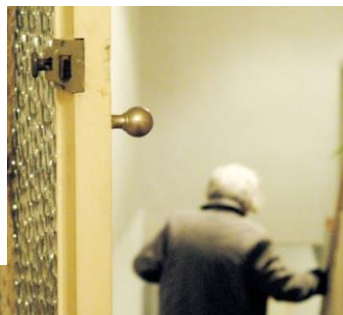
Les différentes stratégies pharmacologiques développées pour retarder la progression de la maladie ne fournissent pas des résultats favorables, contredisant souvent les données épidémiologiques et les résultats de laboratoire

AD2000 Collaborative Group 2004

Les cliniques de la mémoire (Memory Clinic)



ORL e OBV

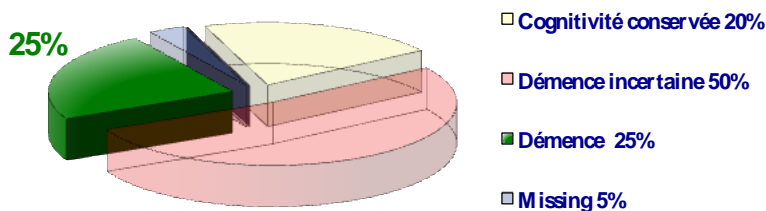


- *Diagnostic et évaluation des syndromes démentiels*
 - Information et prise en charge des patients et de leurs soignants
 - Formation du personnel médical et infirmier
 - Recherche

La consultation de la mémoire Servizio sottocenerino di geriatria

Ospedali Regionali di Mendrisio e Lugano /OIL

Janvier 1998 - Octobre 2014 / N = 2290 patients



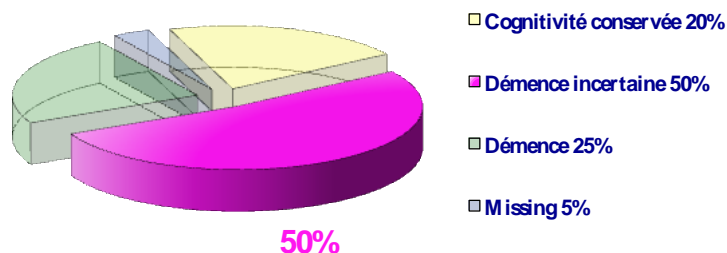
Communiquer le diagnostic

- Les patients atteints de démence veulent savoir leur diagnostic?
- Les médecins informent-ils les patients atteints de démence de leur diagnostic?
- Quelle est l'attitude de la famille à ce sujet?
- Communiquer le diagnostic de démence peut être contre-productif?
- Comment communiquer le diagnostic de démence et, plus généralement, d'une maladie à mauvais pronostic?

La consultation de la mémoire Servizio sottocenerino di geriatria

Ospedali Regionali di Mendrisio e Lugano/OIL

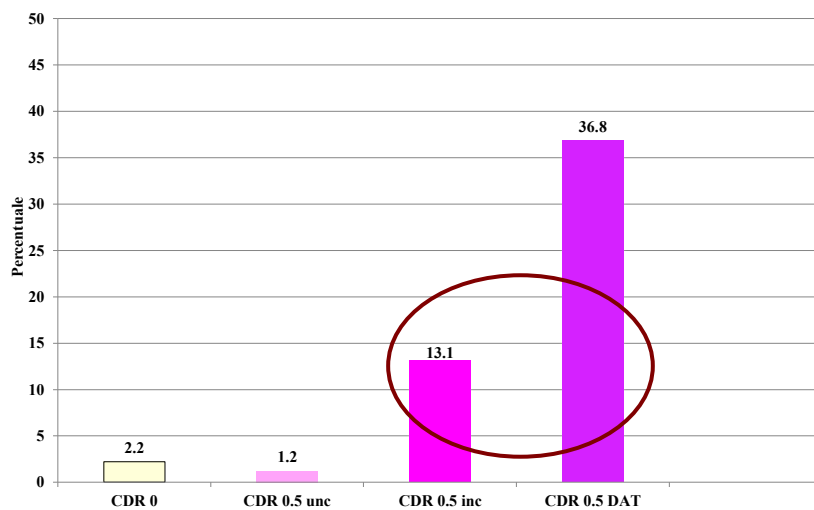
Janvier 1998 - Octobre 2014 / N = 2290 patients



Canton Ticino Study (n=929)

Quadri et al. 2015

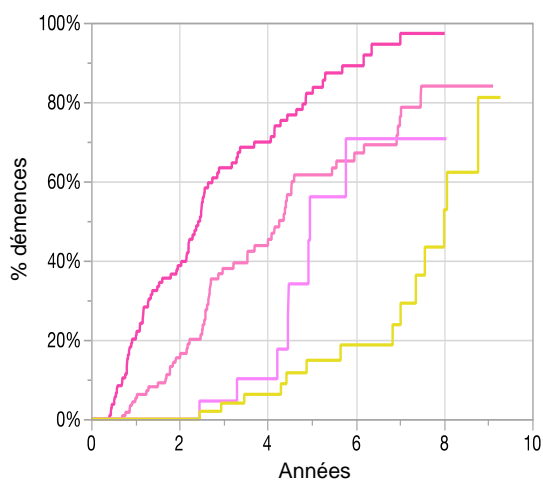
Taux de conversion annuelle en démence



Conversion vers une démence

Quadri et al. 2009

N=34
9





Alzheimer's & Dementia 11 (2015) 58-69

Alzheimer's
&
Dementia

Review Articles

Clinical utility of cerebrospinal fluid biomarkers in the diagnosis of early Alzheimer's disease

Kaj Blennow^{a,*}, Bruno Dubois^b, Anne M. Fagan^c, Piotr Lewczuk^d, Mony J. de Leon^{e,f}, Harald Hampel^b



Advancing research diagnostic criteria for Alzheimer's disease: the IWG-2 criteria

Lancet Neurol 2014;13: 614-29

Bruno Dubois, Howard H Feldman, Claudio Jacova, Harald Hampel, José Luis Molinuevo, Kaj Blennow, Steven T Dekosky, Serge Gauthier, Dennis Selkoe, Randall Bateman, Stefano Cappa, Sebastian Engelborghs, Giovanni B Frisoni, Nick C Fox, Douglas Galasko, Marie-Odile Habert, Gregory A Jicha, Agneta Nordberg, Florence Pasquier, Gil Rabinovici, Philippe Robert, Christopher Rowe, Stephen Salloway, Marie Sarazin, Stéphane Epelbaum, Leonardo C de Souza, Bruno Velás, Pieter J Visser, Lon Schneider, Yaakov Stern, Philip Scheltens, Jeffrey L Cummings

Advancing research diagnostic criteria for the prodromal states of AD

IWG-2 criteria for asymptomatic at risk for AD (A plus B)

- A Absence of specific clinical phenotype (both are required)
- Absence of amnesic syndrome of the hippocampal type
 - Absence of any clinical phenotype of atypical AD
- B In-vivo evidence of Alzheimer's pathology (one of the following)
- Decreased $A\beta_{1-42}$ together with increased T-tau or P-tau in CSF
 - Increased retention on fibrillar amyloid PET

Stage 1

Asymptomatic amyloidosis

- High PET amyloid tracer retention
- Low CSF $A\beta_{1-42}$

Stage 2

Amyloidosis + Neurodegeneration

- Neuronal dysfunction on FDG-PET/fMRI
- High CSF tau/p-tau
- Cortical thinning/Hippocampal atrophy on sMRI

Stage 3

Amyloidosis + Neurodegeneration + Subtle Cognitive Decline

- Evidence of subtle change from baseline level of cognition
- Poor performance on more challenging cognitive tests
- Does not yet meet criteria for MCI

MCI → AD dementia

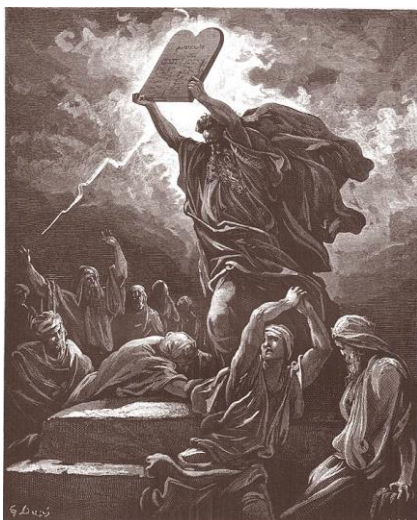
ANALYSIS

TOO MUCH MEDICINE

Political drive to screen for pre-dementia: not evidence based and ignores the harms of diagnosis

David G Le Couteur *professor of geriatric medicine*¹, Jenny Doust *professor of clinical epidemiology*², Helen Creasey *dementia specialist*³, Carol Brayne *professor of public health*⁴

La vérité: un dogme ?



Quelle vérité pour quel patient?

Combien d'espace pour l'espoir après la communication du pronostic?

*Codice deontologico
della Federazione dei medici svizzeri*

Il medico informa in modo comprensibile il suo paziente sui risultati e i referti, sulle previste misure diagnostiche e terapeutiche, sulla prognosi e sui rischi, nonché sui possibili trattamenti alternativi.

Valuta accuratamente il modo con cui intende informare il paziente e quante informazioni il paziente è in grado di sopportare.

Codice deontologico dei medici italiani

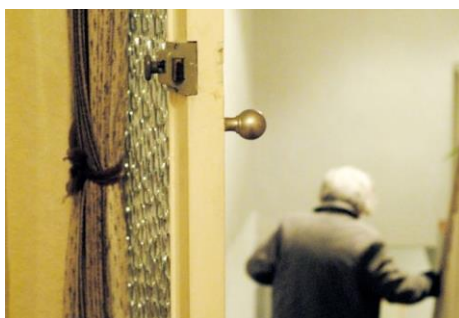
Il medico deve fornire al paziente la più idonea informazione sulla diagnosi, sulla prognosi, sulle prospettive e le eventuali alternative diagnostico-terapeutiche e sulle prevedibili conseguenze delle scelte operate; il medico nell'informarlo dovrà tenere conto delle sue capacità di comprensione, al fine di promuoverne la massima adesione alle proposte diagnostico-terapeutiche. Ogni ulteriore richiesta di informazione da parte del paziente deve essere soddisfatta. Le informazioni riguardanti prognosi gravi o infauste o tali da poter procurare preoccupazione e sofferenza alla persona, devono essere fornite con prudenza, usando terminologie non traumatizzanti e senza escludere elementi di speranza. La documentata volontà della persona assistita di non essere informata o di delegare ad altro soggetto l'informazione deve essere rispettata.

**Avant de lancer la
flèche de la vérité,
plonge-la dans le
miel.**

Proverbe africain

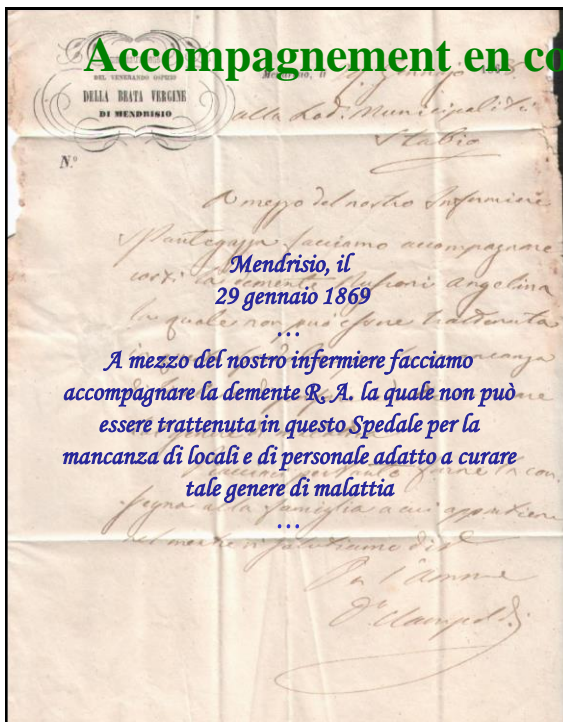


Les cliniques de la mémoire (Memory Clinic)



- Diagnostic et évaluation des syndromes démentiels
- **Information et prise en charge des patients et leurs soignants**
 - Formation du personnel médical et infirmier
 - Recherche

Accompagnement en cours de démence



Au début de la maladie

Signification du diagnostic et
du pronostic
Supervision et sécurité
Compétences de conduite d'automobile
Compétences dans les AVQ
Planification financière

Stade moyen de la maladie

Gestion des troubles du comportement
Hospitalisation de répit
Isolement et fatigue du Caregiver

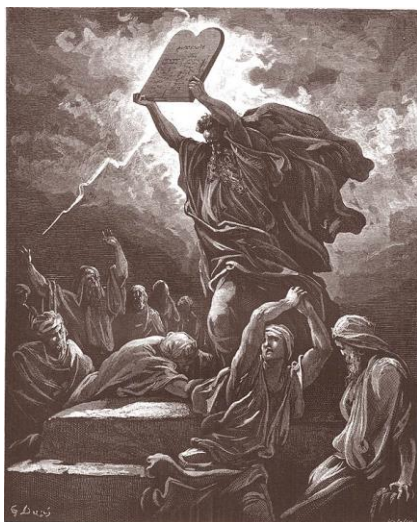
Maladie avancée

Prévention des chutes
Institutionnalisation
Directives anticipées
Soins terminaux

Après la mort du patient

Le deuil
Restructuration de la vie quotidienne
Récupération

Le respect des volontés du patient



*L'incapacité à prendre des
décisions ou des actions*

*Le manque de conscience de la
maladie*

La protection des proches

Conscience de la maladie

- Le terme *anosognosie* concerne la situation de ceux qui, à la suite d'une lésion focale du cerveau, n'ont pas conscience de l'handicap causé par la lésion.
- Le terme de *awareness* est utilisé en psychiatrie pour indiquer la conscience de la maladie.
- Le terme de *insight* est couramment utilisé dans la littérature psychiatrique et surtout psychanalytique et concerne essentiellement ce qu'on peut appeler capacité d'introspection et, par conséquent, la capacité de se reconnaître malade, l'observance du traitement, la capacité à rapporter des événements mentaux anormaux à un phénomène pathologique.

Conscience de la maladie (C), démence et Mild Cognitiv Impairment

- Les déficits de C sont courants dans toutes les démences, mais ont été étudiés principalement dans la maladie d'Alzheimer, dans laquelle ils sont présents dans environ 70% des patients dès le début de la maladie.
- Des données similaires ont également été obtenus pour le MCI, au point de remettre en cause les critères même de diagnostic concernant le déficit subjectif de mémoire.

La charge des caregiver

- Grande dépendance de la personne atteinte d'une démence
- Difficultés de communication de la personne atteinte d'une démence
- Fréquent manque d'un feedback de la part de la personne atteinte d'une démence
- Perception d'une excessive intrusion de la part de la personne atteinte d'une démence et de la part du personnel soignant

Le fardeau des soins

L'impact physique,
consommation médicale accrue

... émotionnelle,
augmentation du stress et des réactions
d'hostilité

... et psychologique,
dépression, anxiété

En conséquence la santé et le bien-être du
CG il représente un outcome du traitement
de la démence



Les décisions de fin de vie



The NEW ENGLAND
JOURNAL of MEDICINE

ESTABLISHED IN 1812 OCTOBER 15, 2009 VOL. 361 NO. 16

The Clinical Course of Advanced Dementia

Susan L. Mitchell, M.D., M.P.H., Joan M. Teno, M.D., Dan K. Kiely, M.P.H., Michele L. Shaffer, Ph.D., Richard N. Jones, Sc.D., Holly G. Prigerson, Ph.D., Ladislav Volcic, M.D., Ph.D., Jane L. Givens, M.D., M.S.C.E., and Mary Beth Hamel, M.D., M.P.H.

ABSTRACT

BACKGROUND

Dementia is a leading cause of death in the United States but is underrecognized as a terminal illness. The clinical course of nursing home residents with advanced dementia has not been well described.

METHODS

We followed 323 nursing home residents with advanced dementia and their health care proxies for 18 months in 22 nursing homes. Data were collected to characterize the residents' survival, clinical complications, symptoms, and treatments and to determine the proxies' understanding of the residents' prognosis and the clinical complications expected in patients with advanced dementia.

RESULTS

Over a period of 18 months, 54.8% of the residents died. The probability of pneumonia was 41.2%, a febrile episode, 52.6%, and an eating problem, 85.8%. After adjustment for age, sex, and disease duration, the 6-month mortality rate for residents who had pneumonia was 46.7%; a febrile episode, 44.5%; and an eating problem, 38.0%. Distressing symptoms, including dyspnea (86.0%) and pain (79.1%), were common. In the last 3 months of life, 46.7% of residents underwent at least one burdensome intervention (hospitalization, emergency room visit, parenteral therapy, or tube feedings). Residents whose proxies had an understanding of the poor prognosis and clinical complications expected in advanced dementia were much less likely to have burdensome interventions in the last 3 months of life than were residents whose proxies did not have this understanding (adjusted odds ratio, 0.12; 95% confidence interval, 0.04 to 0.37).

From the Hebrew SeniorLife Institute for Aging Research (S.L.M., D.K.K., R.N.J., J.L.G.); the Department of Medicine, Beth Israel Deaconess Medical Center (S.L.M., R.N.J., J.L.G., M.B.H.); and the Center for Gerontological Oncology and Palliative Care Research, Dana-Farber Cancer Institute (J.C.P.)—all in Boston; the Center for Gerontology and Health Care Research, Department of Community Health, Alpert Medical School, Brown University, Providence, RI (M.T.); Penn State College of Medicine, Hershey, PA (R.N.J.); and the School of Aging Studies, University of Southern Florida, Tampa, FL. Address reprint requests to Dr. Mitchell at Hebrew SeniorLife, 1200 Centre St., Boston, MA 02131, or at smitchel@heca.harvard.edu.

N Engl J Med 2009;361:1528-38.
©2009 G. D. S. 0895-9178/09/36116-1528\$14.00/0

Les obstacles à l'activation de soins palliatifs (hospice care):

Difficultés d'estimer le pronostic

Incapacité à voir la démence comme une maladie en phase terminale

L'impréparation de la famille et le manque de soutien nécessaire

Attentes des familles

Gwyther, 1990

- **Attitude active**
- **Équipe très professionnelle**
- **Réconfort**
- **Informations**
- **Contrôle de la situation**
- **Choix dans les options de soins**

Early release, published at www.cma.ca on September 3, 2012. Subject to revision.

CMAJ **RESEARCH**

Health care experiences of people with dementia and their caregivers: a meta-ethnographic analysis of qualitative studies

Jeanette C. Prorok MSc, Salinda Horgan PhD, Dallas P. Seitz MD

ABSTRACT

Background: Understanding the health care experience of people with dementia and their caregivers is becoming increasingly important given the growing number of affected individuals. We conducted a systematic review of qualitative studies that examined aspects of the health care experience of people with dementia and their caregivers to better understand ways to improve care for this population.

Methods: We searched the electronic databases MEDLINE, Embase, PsycINFO and CINAHL to identify relevant articles. We extracted key study characteristics and methods from the included studies. We used meta-ethnography to synthesize the extracted information into an overall framework. We evaluated the quality of the primary studies using the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist.

Results: In total, 46 studies met our inclusion criteria; these involved 1846 people with dementia and their caregivers. We identified 5 major themes: seeking a diagnosis, accessing supports and services, addressing information needs, disease management, and communication and attitudes of health care providers. We conceptualized the health care experience as progressing through phases of seeking understanding and information, identifying the problem, role transitions following diagnosis and living with change.

Interpretation: The health care experience of people with dementia and their caregivers is a complex and dynamic process that could be improved for many people. Understanding existing gaps in existing health services, modifying existing services or implementing new models of care to address these gaps may lead to improved outcomes for people with dementia and their caregivers.

Competing interests: None declared.
This article has been peer reviewed.
Correspondence to: Dallas P. Seitz, MD, seitz@psu.edu, dseitz@psu.edu, CMAJ 2012; 184(18):1983-1991, doi:10.1503/cmaj.121795

Conclusion

We found several opportunities to improve the health care experiences of people with dementia and their caregivers. Many of the strategies we suggest for improving service delivery are in keeping with the emphasis on enhancing person-centred care. Through understanding and improving health care experiences, we hope that quality of life and other outcomes will be improved for people with dementia.

Themes	Stages of the health care experience	Health service implications
<ul style="list-style-type: none"> • Confusion • Uncertainty • Resistance 	Seeking information and understanding	<ul style="list-style-type: none"> • Public education and awareness • Tools to assist with raising topic with health care providers
<ul style="list-style-type: none"> • Apprehension • Anxiety • Tension • Relief 	Identifying the problem	<ul style="list-style-type: none"> • Capacity for health care providers to evaluate cognition • Strategies to assist with disclosure of diagnosis
<ul style="list-style-type: none"> • Negotiation 	Role transition	<ul style="list-style-type: none"> • Involving persons with dementia and caregivers in discussions • Discerning treatment wishes and goals with persons with dementia
<ul style="list-style-type: none"> • Goal setting and priorities in relation to progressive illness 	Living with change	<ul style="list-style-type: none"> • Focusing on current needs and next foreseeable care needs

Figure 2: Conceptual framework for the health care experience of people with dementia and their caregivers.

Stratégies d'accompagnement

- Engagement sur une relation à long terme
- Une planification réaliste,
- ... dynamique,
- ... planification anticipée
- Optimisme quant à la réalisation des objectifs à court terme

Efficacité de l'intervention psychosociale sur les caregivers



Journal of Affective Disorders 101 (2007) 75–89



www.elsevier.com/locate/jad

Research report

Systematic review of the effect of psychological interventions on family caregivers of people with dementia[☆]

A. Selwood^{a,*}, K. Johnston^a, C. Katona^b, C. Lyketsos^c, G. Livingston^a

^a Department of Mental Health Sciences, University College London, Archway Campus, Holborn Union Building, Highgate Hill, London, N19 5NL, UK

^b Kent Institute of Medicine and Health Sciences, Canterbury, UK

^c Division of Geriatric Psychiatry and Neuropsychiatry, Suite 308, 550 North Broadway, Baltimore, Maryland 21205, USA

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Available online 14 December 2006

Abstract

Background: Caregivers of people with dementia are at high risk of psychological morbidity and associated breakdown in care. Many psychologically based interventions have been designed to help caregivers of people with dementia. More work is needed to identify which, if any, are helpful for such caregivers.

Method: We conducted a systematic review of the immediate and long term efficacy of different types of psychological interventions for the psychological health of caregivers of people with dementia, using standardized criteria, to assist clinicians in implementing rational, evidence-based management recommendations. We reviewed studies examining the effects of any therapy derived from a psychological approach that satisfied pre-specified criteria. Using the Oxford Centre for Evidence-Based Medicine criteria we rated the quality of each study, extracted data and gave overall ratings to different types of intervention.

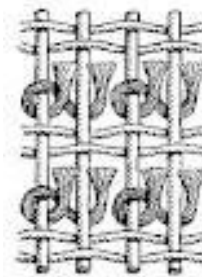
Results: We identified 244 references in our search of which 62 met our inclusion criteria.

Limitations: Our findings are limited by lack of good quality evidence, with only ten level 1 studies identified.

Conclusions: We found excellent evidence for the efficacy of two or more sessions of individual behavioral management therapy centered on the caregiver's behavior in alleviating caregiver symptoms both immediately and for up to 32 months. Teaching caregivers coping strategies to individuals or a group also appeared effective in improving caregiver psychological health both immediately and for some months afterwards. Group interventions were less effective than individual interventions. Education about dementia by itself, group behavioral therapy and supportive therapy were not effective caregiver interventions.

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Keywords: Dementia; Caregivers; Psychological interventions; Systematic review



La chaîne et la trame symbolisent les forces, masculine et féminine, qui façonnent et substance à toute existence.

M. Barracano, Simbologia del tappeto, 1999, Torino