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**Literature Search Results**

**Search completion date:** 22nd September 2011  
**Search completed by:** Jan Badcock

**Enquiry Details**
Why people with dementia are admitted to residential care- possible incontinence issues

**Resources Searched**

- NHS Evidence
- TRIP Database
- igoogle
- CINHAL
- MEDLINE
- EMBASE
- PSYCHINFO
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Full Text Papers
Links are given to full text resources where available. For some of the papers, you will need a free NHS Athens Account. If you do not have an account you can register by following the steps at: https://register.athensams.net/nhs/nhseng/ You can then access the papers by simply entering your username and password. If you do not have easy access to the internet to gain access, please let us know and we can download the papers for you.

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Word documents
Select Edit from the menu, the Find and type in your term in the search box which is presented. The search function will locate the first use of the term in the document. By pressing ‘next’ you will jump to further references.
Effectiveness of nonpharmacological interventions in delaying the institutionalization of patients with dementia: a meta-analysis.

Spijker A, Vernooij-Dassen M, Vasse E, Adang E, Wollersheim H, Grol R, Verhey F.

Abstract
Contemporary healthcare policies are designed to shape the conditions that can help delay the institutionalization of patients with dementia. This can be done by developing support programs that minimize healthcare risks for the patients with dementia and their informal caregivers. Many support programs have been developed, and some of them are effective, but there has been no systematic review with a meta-analysis of all types of nonpharmacological support programs with odds of institutionalization or time to institutionalization as an outcome measure. A systematic review with a meta-analysis was therefore conducted to estimate the overall effectiveness of nonpharmacological support programs for caregivers and patients with dementia that are intended to delay institutionalization. Thirteen support programs with a total of 9,043 patients were included in the meta-analyses. The estimated overall effectiveness suggests that these programs significantly decrease the odds of institutionalization (odds ratio (OR)=0.66, 95% confidence interval (CI)=0.43-0.99, P=.05) and significantly increase the time to institutionalization (standardized mean difference (SMD)=1.44, 95% CI=0.07-2.81, P=.04). A meta-analysis of the best-quality studies still showed a positive significant result for the odds of institutionalization (OR=0.60, 95% CI=0.43-0.85, P=.004), although the time to institutionalization was no longer significant (SMD=1.55, 95% CI=-0.35-3.45, P=.11). The analysis of the intervention characteristics showed that actively involving caregivers in making choices about treatments distinguishes effective from ineffective support programs. Further investigation should be directed toward calculating the potential efficiency of these support programs by applying net-benefit or cost-effectiveness analysis.

Effects of combined intervention programmes for people with dementia living at home and their caregivers: a systematic review.

Smits CH, de Lange J, Dröes RM, Meiland F, Vernooij-Dassen M, Pot AM.

Abstract
OBJECTIVE:
This study reviews the evidence for effects of combined intervention programmes for both the informal caregiver and the person with dementia.

METHOD:
Systematic review. Electronic databases and key articles were searched for effect studies of combined programmes, published between January 1992 and February 2005. The resulting 52 reports were scored according to set inclusion criteria.

RESULTS:
Twenty five reports relating to 22 programmes met the inclusion criteria. Various aspects of caregivers’ mental health and burden were studied. Best results were obtained regarding general mental health. Other aspects often showed modest and varying results. Caregivers' competence was less often addressed. The effects on the cognitive and physical functioning, behavioural problems and survival of the persons with
dementia were modest and inconsistent, whereas their mental health is positively affected and admittance to long stay care is often delayed.

CONCLUSION:
Combined programmes may improve some, not all, aspects of functioning for caregiver and person with dementia. Care professionals must define their programme goals and target groups before advising their clients on a combined programme. Research may focus on the effects of programmes that were introduced fairly recently and on subgroups of caregivers (female caregivers, depressed caregivers and people with dementia, and minorities).

**Predictors of entering 24-h care for people with Alzheimer's disease: results from the LASER-AD study.**
Habermann S, Cooper C, Katona C, Livingston G.

Abstract
OBJECTIVES: Many studies have investigated predictors of people with dementia entering 24-h care but this is the first to consider a comprehensive range of carer and care recipient (CR) characteristics derived from a systematic review, in a longitudinal cohort study followed up for several years.

METHODS: We interviewed 224 people with Alzheimer's disease (AD) and their carers, recruited to be representative in terms of their severity, sex and living situation as part of the LASER-AD study; and determined whether they entered 24-h care in the subsequent 4.5 years. We tested a comprehensive range of characteristics derived from a systematic review, and used Cox proportional hazard regression to determine whether they independently predicted entering 24-h care.

RESULTS: The main independent predictors of shorter time to enter 24-h care were the patient being: more cognitively or functionally impaired (hazard ratio (HR) = 1.09; 95% CI = 1.06-1.12) and (HR = 1.04 95% CI = 1.03-1.05), having a paid versus a family carer (HR = 2.22; 95% CI = 1.39-3.57), the carer being less educated (HR = 1.43; 95% CI = 1.12-1.83) and spending less hours caring (HR = 1.01; 95% CI = 1.00-1.01).

CONCLUSION: As having a family carer who spent more time caring (taking into account illness severity) delayed entry to 24-h care, future research should investigate how to enable carers to provide this. Other interventions to improve patients' impairment may not only have benefits for patients' health but also allow them to remain longer at home. This financial benefit could more than offset the treatment cost.
Prediction of institutionalisation in dementia. A systematic review.
Luppa M, Luck T, Brähler E, König HH, Riedel-Heller SG.
Source

Abstract
BACKGROUND/AIMS:
In the past decades, a substantial number of studies considered factors influencing institutionalisation of persons with dementia. This study reviews recent work on predictors of actual institutionalisation in dementia.

METHOD:
Relevant articles were identified by a systematic search of the literature. Studies were considered which included persons aged 65 and over, and whose results were based on prospective design and on multivariate statistical analyses.

RESULTS:
Forty-two studies were identified. The rate of institutionalisation increased from 20% in the first year after diagnosis to 50% after 5 years. Median time to institutionalisation was estimated between 30 and 40 months. Predictors of institutionalisation were classified according to a provided conceptual framework in the categories sociodemographic and relationship characteristics of persons with dementia and caregivers, primary stressors, secondary stressors and resources.

CONCLUSION:
The overview of research activities in this area showed a lack of methodological strength in a large part of identified studies. Nevertheless, a lot of well-examined and less highlighted predictors could be identified.
Determinants of the Desire to Institutionalize in Alzheimer's Caregivers
Damien Gallagher, Aine Ni Mhaolain, Lisa Crosby, Deirdre Ryan, Loretto Lacey, Robert F. Coen, Cathal Walsh, Davis Coakley, J. Bernard Walsh, Conal Cunningham, Brian A. Lawlor, MD,
Background: The desire to institutionalize is an important predictor of future institutionalization. Few studies have examined potentially modifiable caregiver characteristics which might be the focus of future interventional strategies. Methods: A total of 102 patient/caregiver dyads with Alzheimer’s disease (n = 84) or mild cognitive impairment were recruited through a memory clinic. Cross-sectional analyses of a range of patients, caregivers, and context of care-related characteristics were conducted. Results: Caregiver desire to institutionalize was significantly associated with a number of potentially modifiable variables including caregiver coping style, self-efficacy, depression, burden, and the presence of an unmet service need. In a multivariate analysis, caregiver burden, depression, and nonspousal status were the only significant independent predictors of caregiver desire to institutionalize in a model which correctly classified 80.4% of caregivers. Conclusions: Interventions which seek to reduce caregiver desire to institutionalize should adopt a multifactorial approach to reduce symptoms of burden and depression in caregivers.

Predictors of Nursing Home Admission for Persons with Dementia
Gaugler, Joseph E.; Yu, Fang; Krichbaum, Kathleen; Wyman, Jean F.
Medical Care:
February 2009 - Volume 47 - Issue 2 - pp 191-198
Objective: The objective of this systematic review was to identify factors that consistently predict nursing home admission (NHA) in persons with dementia.

Results: Of 782 relevant studies identified 80 were selected for review based upon eligibility criteria. The most consistent predictors of NHA in persons with dementia included severity of cognitive impairment, Alzheimer disease diagnosis, basic activity of daily living dependencies, behavioral symptoms, and depression. Caregivers who indicated greater emotional stress, a desire to institutionalize the care recipient, and feelings of being trapped in care responsibilities were more likely to admit persons with dementia to nursing homes. Demographic variables, incontinence, and service use did not consistently predict NHA.

Conclusions: Several results seemed to challenge conventional assumptions of what precipitates NHA among persons with dementia. Caregiver stressors in conjunction with care recipient characteristics are important to consider when assessing NHA risk. The findings emphasize the need to construct more complex models of institutionalization when designing risk measures to target interventions.
The impact of incontinence on older spousal caregivers.
Cassells C, Watt E.
BACKGROUND: The role of informal spousal caregivers has increased as the population ages, levels of disability in society increase, and governments seek to restrain expenditure on the provision of institutional health care. Care giving has attracted a vast body of research, largely directed at caregiver burden. Incontinence, however, has been relatively unexplored, despite being a common problem faced by caregivers, and being recognised as a major caregiver burden and predictor of institutional placement.

AIMS: This study began to explore the impact of care recipient incontinence on major care providers, that is, their spouses.

APPROACH: A qualitative approach based on the grounded theory method was used. Eight home-based caregivers of spouses with incontinence were interviewed.

FINDINGS: Data analysis revealed a number of categories, grouped under three major themes: underpinnings, processes and consequences. The underpinnings were lifelong love and friendship, and acceptance; the processes were problem-solving and constant watchfulness. The consequences were role change, financial cost, decreased intimacy, emotional responses, sleeping issues and social isolation.

DISCUSSION: The research highlighted the interconnectedness of factors in the experiences of carers, reinforcing the need for holistic assessment beyond a focus on the "continence issue" alone. Nevertheless, simple interventions could make substantial differences. A framework is proposed which may guide nursing assessment.

A support programme for patients with dementia and their caregivers lowered institutionalisation rates initially.
Forbes D.
Presence of Behavioral and Psychological Symptoms Predicts Nursing Home Placement in Community-Dwelling Elders With Cognitive Impairment in Univariate But Not Multivariate Analysis

Ding-Cheng Chan, Judith D. Kasper, Betty S. Black and Peter V. Rabins
Accepted October 21, 2002.

Background. The role of behavioral and psychological symptoms as an independent risk factor of nursing home placement (NHP) in cognitively impaired elders has been controversial.

Methods. A community sample of 449 cognitively impaired elders and their knowledgeable informants (KIs) was followed for 1 year. Subjects were classified as having dementia (D) or mild cognitive impairment (MCI) (M) using a neuropsychiatric battery of 4 tests. Subject characteristics (behavioral and psychological symptoms, demographic, health related, and health services use) and KI characteristics were entered into the Cox proportional hazard regression analysis.

Results. The incidence rate of NHP was 8.9%. At baseline, 57.7% of subjects had at least 1 behavioral and psychological symptom. Presence of these symptoms was associated with shorter time to NHP only in a univariate analysis. Other factors significant in the multivariate Cox modeling were being white (hazard ratio ), having fair or poor physical health rating (), having greater numbers of difficulties with activities of daily living (), and having a physician's diagnosis of dementia (). An interaction was found between the last 2 variables (), indicating that among those with a diagnosis of dementia, a greater number of difficulties with activities of daily living delayed time to NHP. KI characteristics were not associated with NHP.

Conclusions. Behavioral and psychological symptoms were common, but having these symptoms was not an independent risk factor of NHP. Caregiver characteristics may not play as important a role in determining NHP as subject characteristics. Interventions aimed at improving or maintaining physical or cognitive functioning may have better chances of delaying NHP.

Reasons of informal caregivers for institutionalizing dementia patients previously living at home: the Pixel study.


CONTEXT: Study of the problems and requirements of the main caregiver providing home care for dementia patients that have resulted in the patient being institutionalised.

OBJECTIVES: To determine the reasons for placing the dementia patient in an institution.

RESOURCES: Self-administered questionnaire of 48 questions on the patient and caregiver, including a list of complaints, given to the main caregiver. Medical questionnaire on the patient filled in by the geriatrician.

RESULTS: Data were collected from 109 questionnaires concerning 75 females with dementia (84.7 +/- 6.7 years) and 34 demented males (80.8 +/- 7.4 years). In two-thirds of cases the main caregiver was a female, aged 61.1 +/- 12.1 years. Cognitive disorders were not the main reasons for institutionalizing patients. The most frequent caregiver complaint at the time of institutionalisation was incontinence, followed by withdrawal. The caregiver's main problem resulting in institutionalisation was dependence, with behavioural disorders in second place. A treatment with anticholinesterase for dementia was associated with a live-in career being provided for 20 months longer than in the
case of patients not receiving this treatment. Statistical analysis revealed 6 groups of separate caregiver-patient situations. On the one hand there were those patients who appeared to be easy for the caregiver to cope with: those with no problems, docile patients and passive patients not opposing care. In these cases the caregiver was most often young and male, or not directly related to the patient. On the other hand there were 3 other groups: patients with inappropriate motor behaviours, violent/agitated patients and unmotivated patients who opposed care. These patients lived with an elderly caregiver who had been looking after the patient for several years.

DISCUSSION: Caregivers’ requirements are for help with coping with and preventing dependence. The caregiver suffers terribly from a lack of relief, particularly when young.

CONCLUSION: It is necessary to change the focus of home care for dementia patients towards preventing loss of autonomy and its consequences and to allow for periods of relief for home caregivers.

Caregivers' Reasons for Nursing Home Placement: Clues for Improving Discussions With Families Prior to the Transition
Gwendolen T. Buhr, Maragatha Kuchibhatla, and Elizabeth C. Clipp.
Purpose: This study identifies the relative importance of reasons for institutionalization endorsed by caregivers of patients with dementia; examines the relationship between caregivers’ reasons for institutionalization and indicators of caregiver and patient physical and emotional functioning measured in the prior year; and compares, on these indicators, caregivers who institutionalized their care recipients with caregivers who did not. Design and Methods: Participants were 2,200 caregivers from the National Longitudinal Caregiver Study, including 580 who institutionalized their care recipient during the 3-year interval. Caregivers' reason(s) for institutionalization were examined and correlated with indicators of caregiver and patient physical and emotional functioning. These indicators were used in a proportional hazards model to determine independent predictors. Results: Caregivers’ reasons for placement included (a) the need for more skilled care (65%); (b) the caregivers' health (49%); (c) the patients' dementia-related behaviors (46%); and (d) the need for more assistance (23%). Each of these reasons was significantly associated with indicators in the prior year's survey. This study uniquely demonstrates that caregiving task demand and a single-item measure of caregiver life satisfaction significantly predict placement. Implications: These findings emphasize that caregivers’ reasons have valid underpinnings and that institutionalization of dementia patients results from caregiver and patient factors evident in the year prior to placement. In routine office visits, caregivers should be systematically screened; accounts of low life satisfaction, dementia problem behaviors, or high task demand should cue clinicians that discussions of nursing home placement would be timely and appropriate.
The impact of incontinence on older spousal caregivers.
Cassells C, Watt E.
BACKGROUND: The role of informal spousal caregivers has increased as the population ages, levels of disability in society increase, and governments seek to restrain expenditure on the provision of institutional health care. Care giving has attracted a vast body of research, largely directed at caregiver burden. Incontinence, however, has been relatively unexplored, despite being a common problem faced by caregivers, and being recognised as a major caregiver burden and predictor of institutional placement.

AIMS: This study began to explore the impact of care recipient incontinence on major care providers, that is, their spouses.

APPROACH: A qualitative approach based on the grounded theory method was used. Eight home-based caregivers of spouses with incontinence were interviewed.

FINDINGS: Data analysis revealed a number of categories, grouped under three major themes: underpinnings, processes and consequences. The underpinnings were lifelong love and friendship, and acceptance; the processes were problem-solving and constant watchfulness. The consequences were role change, financial cost, decreased intimacy, emotional responses, sleeping issues and social isolation.

DISCUSSION: The research highlighted the interconnectedness of factors in the experiences of carers, reinforcing the need for holistic assessment beyond a focus on the "continence issue" alone. Nevertheless, simple interventions could make substantial differences. A framework is proposed which may guide nursing assessment.
Sleep Problems and Institutionalization of the Elderly
Charles P. Pollak, Deborah Perlick,
This study examined the role of sleep problems in the decisions of families to institutionalize elderly relatives. Previous work on institutionalization of the elderly has given little attention to the contribution of nocturnal, sleep-related problems. Seventy-three primary caregivers of elders recently admitted to a nursing home or psychiatric hospital were asked to identify the problems the elder was having during the night and day and rate the degree to which these influenced their decision to institutionalize the elder. Seventy percent of the caregivers in each sample cited nocturnal problems in their decision to institutionalize, often because their own sleep was disrupted. The most frequent disruptive nocturnal events were micturition, pain, and complaints of sleeplessness. Sleep problems of the elderly contribute heavily to the decision to institutionalize an elder and thus to the social and economic cost of institutional care. They appear to do this largely by interfering with the sleep of caregivers. The nature, prevalence, and treatability of the sleeping problems of both elders and their caregivers need further study.
Predictors of Institutionalization of Cognitively Impaired Elders Family Help and the Timing of Placement

Joseph E. Gaugler a, Anne B. Edwards b, Elia E. Femia b, Steven H. Zarit b, Mary-Ann Parris Stephens c, Aloen Townsend d and Rick Greene e

Although predictors of nursing home placement have attracted a good deal of attention in gerontological research, the type and amount of family assistance offered to caregivers prior to institutionalization has not been extensively examined. This study analyzed the impact of family help on the timing of placement among cognitively impaired care recipients. Using longitudinal data from the Adult Day Care Collaborative Study, an event-history analysis was performed to determine the effects of family help after sociodemographic characteristics, caregiving stressors, and indicators of caregiver well-being were taken into account. Results showed that caregivers were far less likely to institutionalize their relatives when family members provided overnight help and assisted with activities of daily living care. These findings suggest that specific types of family help play an important role in delaying nursing home placement among older adults suffering from dementia.

Incontinence among elderly community-dwelling dementia patients. Characteristics, management and impact on caregivers.
Ouslander JG, Zarit SH, Orr NK, Muira SA.
SourceMulticampus Division of Geriatric Medicine and Gerontology, UCLA School of Medicine.

Incontinence was identified by 36% of 184 caregivers as a problem in their care of older community-dwelling patients with dementia. Incontinent dementia patients had greater impairment of cognitive function and more frequent behavioral problems than did patients without incontinence. Burden scores were higher among caregivers of incontinent patients, but multiple regression analyses indicated that factors other than incontinence contributed more to perceived burden. Follow-up interviews revealed that incontinence had played an important role in most decisions to institutionalize among caregivers of patients who were placed in a nursing home between interviews; it rarely, however, was the primary reason. The majority of incontinent patients still residing in the community were being managed by nonspecific techniques such as diapers and toileting schedules. These data emphasize the need to educate community caregivers of dementia patients in the appropriate management of incontinence and the need for further research on methods of effectively targeting assessment and treatment strategies to this patient population.
Predictors of institutionalization for people with dementia living at home with a carer.
Hope T, Keene J, Gedling K, Fairburn CG, Jacoby R.
OBJECTIVE: This article examines the relationships between behaviour, psychological functioning, the caring environment and subsequent institutionalization in patients with dementia living at home with a carer.

DESIGN: Longitudinal study of behaviour in dementia, with a nested case-control study to investigate predictors of institutionalization.

SETTING: Subjects with dementia, known to service, living at home with a carer. All lived in Oxfordshire, UK.

PARTICIPANTS: 100 people with dementia (Alzheimer's disease and/or vascular dementia) who were living at home with a carer at the start of the study.

MEASURES: At 4-monthly intervals, the carers were interviewed and the subjects with dementia were assessed cognitively. Subjects' behaviour and psychological functioning were assessed using the Present Behavioural Examination.

RESULTS: The characteristics which best predicted institutionalization 1 year later were: excessive night-time activity; immobility or difficulty in walking; incontinence; being away from a carer for more than 16 hours a week; and being cared for by a female. Aggressive behaviour was not associated with an increased chance of entry into an institution 1 year later, although it was more prevalent 4 months before entering an institution.

CONCLUSIONS: Both behaviour and psychological functioning and the caring environment can help in predicting which patients with dementia currently living at home will enter an institution 1 year later. These predictors are not the same as those which are the immediate cause of institutionalization.
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1. Incontinence and troublesome behaviors predict institutionalization in dementia.

Citation: Journal of Geriatric Psychiatry and Neurology, January 1992, vol./is. 5/1(45-52), 0891-9887 (Jan-Mar 1992)

Author(s): O'Donnell, Brian F; Drachman, David A; Barnes, Heather J; Peterson, Karen E; et al

Language: English

Abstract: Studied factors predicting the early institutionalization of demented patients in 143 outpatients (mean age 71 yrs). Four types of factors were evaluated for prognostic value: severity of functional impairment, behavioral disorders, individual patient characteristics, and type of caregiver. Ss were reevaluated at 6-mo intervals. 51 Ss were institutionalized before the end of the study. Behaviors that predicted imminent nursing home placement could be characterized as troublesome, disruptive, or obstreperous behaviors that pose extremely difficult management problems for caregivers. Specific behavioral disorders that predicted institutionalization included incontinence, paranoia, aggressive behavior, irritability, hallucinations and delusions, loss of regard for the feelings of others, and inappropriate sexual behavior. Neither individual patient characteristics nor caregiver relationship to the patient influenced institutionalization. (PsycINFO Database Record (c) 2010 APA, all rights reserved)

Publication Type: Journal; Peer Reviewed Journal

Source: PsycINFO

2. Coping, caring and stress: a study of stroke carers and carers of older confused people.

Citation: British Journal of Clinical Psychology, 01 September 1994, vol./is. 33 (Pt 3)/(333-344), 01446657

Author(s): Matson, N

Language: English

Abstract: The dementias and strokes are chronic conditions often occurring at older ages. Most sufferers are cared for at home and, in this context, many research studies have described high levels of stress experienced by their carers. The present study, looking mainly at spouse carers of stroke victims (N = 36) or older confused people (N = 37), examined the possibility that the ways in which carers cope may be associated with their levels of stress and depression. A number of measures of behaviour disturbance and coping were developed and utilized. Multiple regression analyses supported the involvement of some aspects of coping in relation to carer stress and depression, particularly the coping strategy of Non-confronting and a Quality of Coping index—the former being positively and the latter negatively associated with stress and depression. Implications for intervention work with carers of stroke victims or carers of older confused people are discussed.

Publication Type: journal article

Source: CINAHL

3. The impact of the symptoms of dementia on caregivers.

Citation: Br J Psychiatry, January 1997, vol./is. 170/1(62-8), 0007-1250 (1997 Jan)

Author(s): Donaldson, C

Abstract: Symptoms of dementia as stressors to carers. 34 refs.

Source: BNI

4. Major strain and coping strategies as reported by family members who care for aged demented relatives.

Citation: J Advanced Nursing, October 1997, vol./is. 26/4(683-91), 0309-2402 (1997 Oct)

Author(s): Almberg, B

Abstract: Research on the burden and burnout experiences. 31 refs.
5. Demented and chronic depressed patients attending a day hospital: Stress expressed by carers.

Citation: International Journal of Geriatric Psychiatry, September 1998, vol./is. 13(9)(642-643), 0885-6230;1099-1166 (Sep 1998)

Author(s): Rosenvinge, Henry; Jones, Debbie; Judge, Elizabeth; Martin, Anne

Language: English

Abstract: After further analysis of their study data, the authors offer several additions and alterations to their original paper (H. Rosenvinge et al, 1998). Issues addressed include (1) the difficulty of making direct comparisons of severity between 2 groups of patients; (2) results of a comparison between the authors' data on carer stress severity and a consecutive case referral study (C. Wijeratne and S. Lovestone, 1996); (3) data on the relationship between duration of caregiving and carer stress; and (4) data on the relationship between specific behavior difficulties and carer stress. (PsycINFO Database Record (c) 2010 APA, all rights reserved)

Publication Type: Journal; Peer Reviewed Journal

Source: PsycINFO

Full Text: Available in fulltext at EBSCO Host

6. Social and depressive stress suffered by spouses of patients with mild dementia.

Citation: Scandinavian Journal of Primary Health Care, December 1998, vol./is. 16(4)(242-6), 0281-3432;0281-3432 (1998 Dec)

Author(s): Braekhus A; Oksengard AR; Engedal K; Laake K

Language: English

Abstract: OBJECTIVE: To identify stressors and their correlates in spouses of patients with mild dementia. DESIGN: Retrospective study of patient records. SETTING: Patients attending a Memory Clinic at Ullevaal Hospital in Oslo. SUBJECTS: 92 mildly demented patients living at home (mean age 75.7 years, 51% women, mean MMSE score 22.3) and their spouses. MAIN OUTCOME MEASURES: Frequency and types of stress suffered by spouses using validated and factor-analyzed instruments as measures. RESULTS: Twenty-five per cent or more of the spouses reported often/always having problems with the following: being depressed by the situation, having difficulties getting away on holiday, social life being affected, household routines being upset, and sleep being interrupted. Factor analysis of the Greene Caregiver Stress Scale (15 items) identified two factors; 'Social stress' and 'Depressive stress'. Social stress was associated with the patient's I-ADL level, and depressive stress with mood and behaviour of the patient. The depressive symptomatology of the patient as expressed by the spouses was related to both depressive and social stress, whereas cognitive function, as measured by the MMSE, was not an independent predictor of carer strain. CONCLUSION: Even in mildly demented patients, symptoms of carer stress are frequent. Supportive strategies such as early diagnosis, information for carers and intervention strategies are discussed.

Publication Type: Journal Article

Source: MEDLINE

Full Text: Available in fulltext at EBSCO Host

7. Caring for family carers and people with dementia.

Citation: International Journal of Psychiatric Nursing Research, 01 October 2000, vol./is. 6/2(684-694), 09680624

Author(s): Lo R; Brown R
Caring at home for a relative with dementia is a choice for both the person with a 
dementing illness and the carer. This caring may be a rewarding experience or it may 
cause further morbidity in the older patient and feelings of frustration, anger and 
powerlessness in both carer and patient. Psychological morbidity such as depression may 
because a consequence for both the carer and patient in poor choice placement and 
relationships. This paper examines some major issues surrounding dementia management. 
A broad range of interventions are reviewed that may assist prevention of conflict and the 
worsening of the dementia condition for the patient, which may also be effective in the 
lessening of stress for the carers.

8. Predictors and incidence of urinary incontinence in elderly Canadians with and without dementia--A five-year 
follow up: The Canadian Study of Health and Aging.

Determined the importance of socio-demographic and medical factors, cognitive and 
functional status as predictors of the development of urinary incontinence, and estimated 
five-year incidence by sex and age group. Participants (aged 65 yrs and older) from the 
Canadian Study of Health and Aging who underwent a clinical examination in 1992 and 
were continent for urine at the time were followed up and their continence status was 
again determined in 1997. Multivariate logistic regression models with daily incontinence 
and daily or less than daily incontinence as the outcomes were developed separately for 
306 males and 520 female survivors. Predictor variables were introduced in the following 
chunks: socio-demographic factors; cognitive status; functional status, diabetes and 
stroke. Results indicated that the incidence of urinary incontinence was higher in women 
than in men, and increased by age in both men and women. Incontinence increased 
dramatically with severity of dementia, less so with physical immobility. It is concluded 
that the extent of assessment and management should be carefully tailored to each 
individual patient. (PsycINFO Database Record (c) 2010 APA, all rights reserved)

9. Urinary and faecal incontinence and dementia.

Reviews the nature and pathophysiological mechanisms of loss of continence in people 
with dementia and addresses the basic diagnostic and therapeutic challenges that are 
presented by this common clinical problem. Issues discussed include urinary continence, 
the influence of aging, morbidity and dementia on urinary continence, clinical 
classification of urinary incontinence, and assessment and management of elderly people 
with urinary incontinence and dementia. Also discussed is faecal continence and the 
management of faecal incontinence in older people with dementia. (PsycINFO Database 
Record (c) 2010 APA, all rights reserved)
10. Stress in carers of individuals with dementia and Community Mental Health Teams: an uncontrolled evaluation study.

**Citation:** Journal of Advanced Nursing, May 2005, vol./is. 50/3(325-33), 0309-2402; 0309-2402 (2005 May)

**Author(s):** Hoskins S; Coleman M; McNeely D

**Language:** English

**Abstract:**
AIM: The aim of this was to evaluate the effectiveness of interventions provided by a Community Mental Health Team (CMHT) in reducing stress in carers of individuals with dementia.

BACKGROUND: The CMHT had been created to working specifically with older people with mental health problems and their carers. Following initial multidisciplinary assessment a range of interventions were provided to both clients and carers according to assessed need. There is an established need for mental health services to focus on the need of carers and the study attempts to see if the interventions provided were useful in reducing carer stress.

METHOD: The study used a time series design over a 2-year period on all referrals to the CMHT. All carers of individuals with dementia or clearly identified memory problems were invited to participate and a total of 26 carers consented and participated in all stages of data collection. Data were collected on initial assessment, as well as 3 and 6 months following the initial assessment using the Caregiver Strain Index (CSI). A questionnaire was also administered which collected basic demographic information and details of symptoms demonstrated by the carer's relatives.

RESULTS: On initial assessment the mean CSI score for the overall sample was 9.23. The mean CSI reading at 3 months (6.63) and 6 months period (4.12) demonstrated statistically highly significant reductions in carer stress (P = 0.000). A linear stepwise regression analysis of the impact of the different interventions on reductions in the CSI scores showed a statistically significant relationship between respite care and reduction in carer stress (B = 1.705, t = 2.586, P = 0.017).

CONCLUSION: The results add support to the role of multidisciplinary community based services for individuals with dementia, offering a range of interventions to both clients and their carers, in reducing carer stress. The authors also argue for the routine use of the CSI in such teams as means of monitoring the well-being of carers as well as evaluating the effectiveness of service delivery.

**Publication Type:** Journal Article

**Source:** MEDLINE

**Full Text:** Available in fulltext at EBSCO Host

11. Carer training project for the management of behavioural and psychological symptoms of dementia (BPSD) by home-based carers: phase 2.

**Citation:** Geriaction, 01 July 2005, vol./is. 23/2(5-11), 10324410

**Author(s):** Dicker BS; Chawla S; Preston N

**Language:** English

**Abstract:**
Behavioural and psychological symptoms of dementia (BPSD) have been identified in several studies as the single greatest contributor to caregiver stress. Research has also shown that training carers of persons with dementia reduces carer stress, can delay residential placement and improves the quality of life of carer and care recipient. An evidence-based training package that focuses specifically on BPSD management was developed and trialed with 50 home-based carers.; The package utilises a one-to-one, customised (modular) approach and can be delivered in the carer's home. Pre- and post-tests administered to carers demonstrated statistically significant learning gains. Evaluation questionnaires completed by carers following delivery of the training indicated that statistically significant gains were made in self-perceived knowledge of dementia and BPSD, management of BPSD, care-giving ability and stress reduction. With the exception of stress reduction, these gains were maintained six and 12 months post-training.; Twelve months post-training, however, carer stress had returned to near pre-intervention levels. A customised, evidence-based approach to training home-based
carers increased carer competence and confidence in the management of BPSD and had an immediate effect on reducing carer stress.

12. Dementia and residential placement: a view from the carers' perspective.

Citation: Qualitative Social Work, 01 June 2006, vol./is. 5/2(187-215), 14733250

Author(s): Chene B

Language: English

Abstract: The purpose of this research is to discover dementia carers' lived experience when they have relinquished full-time care. It is assumed that once family members make a decision to relinquish full-time care, the stresses of day-to-day care-giving will be eliminated.

Twenty primary caregivers from Aged Care/Aged Psychiatry Units in Melbourne were recruited through a consecutive sampling procedure to participate in the study.; The Stress Process Model was utilized to explain why dementia caregiving is so stressful. A mixed-method research approach that consisted of qualitative and quantitative methodologies was utilized.; In-depth interviews with caregivers revealed the difficult and stressful aspects of dementia caregiving while waiting for residential care. A majority of dementia care-givers had experienced both complex and traumatic admissions to the Aged/Psychiatric Inpatient Units. Carers felt alone in making the 'most difficult' decision to relinquish full-time care, and these carers experienced loss, sadness and resignation after having made this decision.; Carers of Non-English Speaking Background had a compromised life satisfaction and poor psychological health. One-half of all caregivers who participated in the study were seen to be at risk of depression that would warrant professional intervention. Results that have not previously been reported in the dementia caregiving literature were the compromised life satisfaction and poor psychological health of carers from Non-English Speaking Background.; The study concludes that social workers and other professionals need to become aware of the consequences of placement so that increased support can be offered to dementia caregivers during this difficult phase of caregiving. The practice implications include the identification of at risk carer groups and the need for appropriate supports for dementia caregivers at all stages of the caring process.

13. Impact of diagnostic disclosure in dementia on patients and carers: qualitative case series analysis.

Citation: Aging & Mental Health, 01 September 2006, vol./is. 10/5(525-531), 13607863

Author(s): Derksen E; Vernooij-Dassen M; Gillissen F; Olde Rikkert M; Scheltens P

Language: English

Abstract: Adequate diagnostic information can be considered a basic intervention in dementia care. However, clear diagnostic disclosure in dementia is not yet regular practice and the evidence regarding patients' preferences for or against disclosure is scarce. The aim of this study was to give an in-depth description of the impact of receiving the diagnosis of dementia, both on patients and the patients' proxies. The method used was the design of a grounded theory interview study. Analysis of the interviews revealed that disclosure had an impact on three key domains: awareness of dementia, partnership, and social relationships. Most patients and carers reported that they had experienced the disclosure of the diagnosis as a confirmation of their assumptions. A minority of patients and carers felt threatened and shocked by the diagnosis, because they did not expect it. The findings of this analysis challenge current opinions and practice about diagnostic disclosure like obstacles anticipated by clinicians such as inducing negative feelings and causing harm. Disclosure of the diagnosis of dementia can generally be carried out without introducing stress for the patient or carer and facilitates guidance. Therefore regular practice should include the careful planning and performance of diagnostic disclosure.
14. Use of the Zarit Scale for assessing caregiver burden and collapse in caregiving at home in dementias.

Citation: Int J Geriatric Psychiatry, October 2007, vol./is. 22/10(957-62), 0885-6230 (2007 Oct)
Author(s): Gort, A; Mingot, M; Gomez, X
Abstract: Research in Spain into the use of the Zarit Scale to identify the characteristics of burden in family or friends of people with dementia and to establish risk factors for the collapse of caregiving at home. Issues concerning behavioural disorders and carers who were not living with the patient are highlighted. 24 refs.

15. An evaluation of a specialist multiagency home support service for older people with dementia using qualitative methods.

Citation: International Journal of Geriatric Psychiatry, January 2008, vol./is. 23/1(65-72), 0885-6230; 0885-6230 (2008 Jan)
Author(s): Rothera I; Jones R; Harwood R; Avery AJ; Fisher K; James V; Shaw I; Waite J
Language: English
Abstract: BACKGROUND: Standard home care support for people with dementia has been criticised in statutory inspection reports, and may lead to unnecessary crises, hospital or care home admissions.OBJECTIVE: To establish whether a specialist multiagency home care service for older people with dementia delivered better quality care than standard services, and how any improvements were achieved.DESIGN: Qualitative study, using semi-structured interviews, focus groups and small group interviews.SETTING: Two demographically similar areas in Nottingham, one served by a specialist home care team, the other by standard services.PARTICIPANTS: Twenty-seven service users, 18 family carers, 17 home care workers, 20 health/social care professionals, across both services.RESULTS: The specialist service demonstrated greater flexibility and responsiveness to the particular needs and circumstances of service users and family carers, who were encouraged to participate in routine decision-making and activities. By sharing responsibilities, the specialist service helped reduce carer stress and prevent crises. These outcomes depended on the configuration of the service, including multidisciplinary health and social services input, carereworker autonomy and independence, continuous reassessment of clients' circumstances and preferences and the capacity to develop long-term relationships, through carerworker continuity. The standard service, which used a task-orientated approach, lacked these characteristics.CONCLUSIONS: This study provides evidence of the benefits of a specialist multiagency home support service over standard home care, in the opinion of service users, carers and carerworkers, and defines the operational model that achieves this. Findings confirm best practice recommendations, based on models of dementia care which emphasise respect for 'personhood'.


Citation: Int J Geriatric Psychiatry, January 2008, vol./is. 23/1(60-4), 0885-6230 (2008 Jan)
Author(s): Neil, W; Bowie, P
Abstract: Research in the north of England into the development of a carer self-report questionnaire to assess the distress caused by patients' neuropsychiatric symptoms. The effectiveness of the Behavioural and Psychological Symptoms Questionnaire is discussed. 20 refs.

Source: BNI
Full Text: Available in fulltext at EBSCO Host

17. Promoting continence and managing incontinence with people with dementia living at home: one more challenge for integration.

Citation: J Integrated Care, February 2009, vol./is. 17/1(15-25), 1476-9018 (2009 Feb)
Author(s): Drennan, V; Cole, L
Abstract: Outline of the challenges involved in developing integrated services for older adults as illustrated by a case study of people with dementia and incontinence problems who are living at home. Frameworks and priorities to support planning and commissioning are discussed. 78 refs.
Source: BNI
Full Text: Available in fulltext at EBSCO Host

18. A systematic literature review of incontinence care for persons with dementia: the research evidence.

Citation: J Clinical Nursing, February 2010, vol./is. 19/3-4(303-12), 0962-1067 (2010 Feb)
Author(s): Haggglund, D
Abstract: Systematic review of research examining the effectiveness of strategies used to assess, manage and prevent urinary/faecal incontinence in people with dementia. The impact of various management/prevention methods, including prompted/timed voiding, bladder/bowel/pelvic floor muscle training, incontinence aids, catheterisation and laxative use, was investigated. Challenges of maintaining dignity are considered. 54 refs.
Source: BNI
Full Text: Available in fulltext at EBSCO Host


Citation: Geriatrics & Gerontology International, April 2010, vol./is. 10/2(177-182), 1444-1586;1447-0594 (Apr 2010)
Author(s): Miu, Doris K. Y; Lau, Szeting; Szeto, Samuel S. L
Language: English
Abstract: Aim: Urinary incontinence associated with dementia can result in medical comorbidities. We aimed to determine the prevalence of urinary incontinence and to identify the etiology and factors associated with urinary incontinence in dementia patients. Methods: Patients with an Mini-Mental State Examination (MMSE) score of more than 10, attending the memory clinic were recruited. Basic demographic data, types and duration of dementia, use of cholinesterase inhibitor and other drugs with anticholinergic effects, carer stress and presence of urinary incontinence in the previous 6 months were recorded. Urodynamic studies were carried out in those patients with urinary incontinence. Results: One hundred and forty-four subjects with a mean age of 78 years (standard deviation 6.8) were included. Forty-eight (33.3%) had urinary incontinence. There was no statistically significant difference between continent and incontinent groups regarding age, MMSE, duration of dementia, use of cholinesterase inhibitor and of drugs with anticholinergic effects. Presence of nocturia of more than twice per night (odds ratio [OR] 4, 95% confidence interval [CI] 1.7, 9.2), use of walking aids (OR 2.6, 95% CI 1.1, 5.9) and male sex (OR 1.36, 95% CI 1.1, 5.2) were independent predictors of urinary incontinence. Urodynamic studies showed that 21 subjects had detrusor overactivity, 13 had bladder outlet obstruction, two with low compliance bladder, two with small bladder capacity, four with detrusor hyperactivity and impaired contractility. Conclusion: Urinary incontinence commonly occurs in dementia subjects. Poor mobility and presence of
nocturia increase the risk of urinary incontinence. Correction of the possible reversible factors may help to reduce the prevalence of urinary incontinence in patients with dementia and reduce carer stress. (PsycINFO Database Record (c) 2010 APA, all rights reserved) (journal abstract)

**Publication Type:** Journal; Peer Reviewed Journal  
**Source:** PsycINFO

**20. Incontinence in patients with dementia.**

**Citation:** Br J Nursing, June 2011, vol./is. 20/12(721-5), 0966-0461 (2011 24 Jun)  
**Author(s):** Price, H  
**Abstract:** Management of incontinence in patients with dementia. Prevalence, causes, assessment and diagnosis are considered and behavioural techniques, increase in fibre and fluid intake, promotion of mobility and use of drug therapy and incontinence pads are discussed. Role of the nurse in continence promotion and ethical issues in treatment are outlined. 38 refs.  
**Source:** BNI  
**Full Text:** Available in fulltext at EBSCO Host