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Service utilisation and family support of people with dementia: a cohort study in England

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Running header: Service utilisation and family support in dementia cohort

2-6 key words: Health and social services; Informal care; dementia

4 key points:

- People with dementia living alone in their own homes receive larger social care packages than those with live-in carers
- Live-in carers report very high caring time commitments
- The cost of residential care exceeds the cost of social care, but when the costs of social care and informal care are combined, the situation is less clear cut
- Carer stress reduced after patient admission to care homes

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Structured abstract

Objectives: To compare costs of caring for people with dementia in domiciliary and residential settings, central England.

Methods: A cohort of people with dementia was recruited during a hospital stay 2008-10. Data were collected by interview at baseline, and six and 12 month follow-up, covering living situation (own home with or without co-resident carer, care home); cognition, health status and functioning of person with dementia; carer stress; utilization of health and social services; informal (unpaid) caring input. Costs of formal services and informal caring (replacement cost method) were calculated. Costs of residential and domiciliary care packages were compared.

Results: Data for 109 people with dementia were collected at baseline; 95 (87.4%) entered hospital from their own homes. By 12 months, 40 (36.7%) had died and 85% of the survivors were living in care homes. Over one half of people with dementia reported social care packages at baseline; those living alone had larger packages than those living with others. Median caring time for co-resident carers was 400 minutes /day; 10 hours /week for non co-resident carers. Residential care was more costly than domiciliary social care for most people. When the value of informal caring was included, the total cost of domiciliary care was higher than residential care, but not significantly so. Carer stress reduced significantly after the person with dementia entered a care home.

Conclusions: Caring for people with dementia at home may be more expensive, and more stressful for carers, than care in residential settings.

245 words

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Introduction

Dementia typically results in progressive loss of function and behaviour control, particularly in the last few years (Burns 2009). People with dementia become highly dependent on family and friends (i.e. informal or unpaid carers) and on health and social services (Alzheimer's Research Trust 2010); many eventually move to care homes. Care costs rise with disease progression (Souetre et al 1999; Wolstenhomle et al 2002; Hux et al 1998). Since residential care represents a significant component of costs (Trabucchi 1999; House of Commons 2008; Knapp and Prince 2007), policy has focussed on community care enabling people with dementia to stay in their own homes for as long as possible (Trabucchi 1999; Bosanquet 2001). However, caring for someone with dementia is time consuming and stressful (Langa et al 2001; Schneider et al 2002; Harrow et al 2004; Walker et al 2006), and also imposes significant financial pressures on families (Coduras et al 2010; Schneider et al 2003).

Research to date has focused on outcomes of people with dementia during hospital admission (Morrison and Siu 2000; Mecocci et al 2005; Sampson et al 2006; 2009; Cowdell 2010; Mukadem and Sampson 2011; Alzheimer's Society 2009 ; Digby and Bloomer 2013), or after care home placement (Scocco et al 2006; Achterberg et al 2006), and few studies compare domiciliary with residential care. This paper reports the findings of a study that recruited people with dementia during a hospitalisation, and followed them, and their carers, for 12 months. We compare the formal and informal caring costs of those in domiciliary and residential settings; outcomes for people with dementia and carers are reported more fully elsewhere (Authors 1; 2; 3).

Methods:

Recruitment

We recruited participants through the hospital liaison psychiatric services of two general hospitals (1080 and 149 beds) in a single NHS Trust in central England between November 2008 and February 2010. The liaison services take referrals of people ≥ 65 years from all parts of the hospitals. Patients were eligible if they had a diagnosis of dementia (DSM-IV), and no severe or life threatening physical illness. Carers were identified with the help of ward staff. Some carers lived with the person with dementia, but

others did not (if the person with dementia lived in a care home, or alone). The co-resident carer of four people with dementia was too frail to participate and another person was designated the carer for the purposes of the research. Consent from the person with dementia, or where capacity was lacking from a relative, was obtained. Carers provided separate consent. Ethical approval was obtained from the local NHS Research Ethics Committee.

Data collection

We collected baseline data about the person with dementia and designated carer during the hospital stay (age, gender, living situation prior to hospitalisation, caring arrangements, ethnicity, employment status). Participants were followed up at six and 12 months after discharge in the place of residence of the person with dementia. Data were collected by two researchers through joint interviews with the person with dementia and carer. Reason for the hospitalisation and length of stay were collected retrospectively from hospital records.

The health status of the person with dementia was assessed at each time point using: the 30 item Mini Mental State Examination (MMSE) to indicate cognitive impairment (Folstein et al 1975); the Clinical Dementia Rating (CDR) for dementia stage (Morris 1993); the total number of acute and chronic co-morbidities for physical health (Burvill et al 1990); the Instrumental Activities of Daily Living (IADL) index for level of independence (Lawton and Brody 1969). Carer psychological wellbeing (stress) was measured using the 12 item General Health Questionnaire (GHQ, Goldberg and Williams 1988). At six month follow-up, we asked participants about the hospital discharge process: uncertainties, delays and underlying reasons. We noted all changes in residency at each follow-up point so that patient pathways could be constructed. We recorded care home types, fees and payers.

Formal and informal care and costs

We designed a series of questions based on the Client Service Receipt Inventory (CSRI), to capture the health and social services received by the person with dementia at each assessment point (Chisholm et al 2000). Health services included were: hospital in and out patient; A&E; primary care (GP, practice nurse); community care (district nurse, health care assistant; psychiatrist and mental health professionals; allied health professionals; care manager / social worker; continence supplies). Social services were: personal care; home help; transport; meals; day care). Participants were asked to recall

utilisation in the prior six months for health care (one month for social care) preceding each interview. We also asked about the extent to which payment was from personal funds.

Designated carers that did not live with the person with dementia were asked to estimate the number of hours each week they spent caring. Co-resident caring time was measured using the Caregiver Activity Survey (CAS) which asks for the minutes per day spent on six different tasks (communication, transport, dressing, eating, grooming and supervision) (Davis et al 1997; Marin et al 2000). We asked all carers if they had taken time off, cut down or given up work to care for the person with dementia, and to report help provided by persons other than themselves.

Analysis

We compared baseline (pre hospitalisation) characteristics of people with dementia and carers living in different situations (residential care, domiciliary alone, domiciliary with others). Associations between baseline characteristics (living situation, age, gender, CDR, MMSE, IADL, number of co-morbidities, medications and hospitalisations in prior six months) and mortality and care home entry were explored, using appropriate statistical tests. Factors associated with uncertainties and delays in the discharge process were investigated.

We analysed use of both formal and informal care by type of service, time period and living situation using medians and inter quartile range (IQR), due to the skewed nature of the data. Monthly data on social services, and daily data on informal care were increased to six monthly values, to be consistent with the health care data.

Costs of health care were calculated in British pounds, 2010 (the year when most data were collected), by applying nationally validated unit costs, inclusive of all oncosts, qualifications and overheads (Curtis 2010) to individual level data on resource use for each service. Inpatient costs were obtained from local financial managers. We first amalgamated health care costs into two categories (hospital and primary/community). These were then summed to give the total cost per person with dementia at each assessment point. Caring costs comprised the sum of social and informal care (from the main and secondary carer). We used national tariffs to value social care (Curtis 2010). Replacement cost methods were used to value informal caring hours, based on the national rates for a Local Authority home care worker (Curtis 2010) applied to median utilisation. We compared mean and median costs for the main

categories of health, social and informal care for participants in different living situations (own home alone, own home with others, care home).

Results

Recruitment and baseline description of the sample

We recruited 112 people with dementia (six able to provide own consent) and carers. One dyad withdrew before providing any data, and two others were excluded due to large amounts of missing information. Of the remaining 109 patients, 15 (13.8%) were recruited in the smaller of the two hospitals. There was no significant difference between participants from the two hospitals on any baseline characteristic (data not shown).

Fourteen (12.8%) participants entered hospital from a care home; the rest from a domiciliary setting of whom 63 (66.3%) lived alone (Table 1). The majority of people with dementia were women; most carers were men. People admitted from care homes tended to be older, and have more advanced dementia, than those from a domiciliary situation. The carers of care home residents tended to report fewer psychological symptoms than domiciliary carers (Table 1).

Table 1 goes here

There was no statistically significant difference between people recruited from different living situations with respect to: time since dementia diagnosis (overall 28 (25.7%) \geq 3 years), number of co-morbidities (mean 2.59, SD 1.67), number of medications (mean 4.15, SD 3.03), proportions taking anti dementia medications (34 /102, 33.3%, 7 missing). The mean (SD) length of the index hospitalisation was 47.75 days (29.98) range 4 – 161; the primary reasons were falls (n=33, 30.3%), fractures (11, 10.1%), chest or urinary infections (17, 15.6%). Other reasons included mobility problems, dehydration, wandering / confusion, CVA, tumours and bowel obstruction.

Mortality

Over one third (n=40, 36.7%) of people with dementia died within 12 months (Table 2). Mortality was associated with admission to hospital from a care home, rather than a domiciliary location (n =10/14, 71.4% vs. 30/95, 31.6% died, chi square $p = .012$) and (marginally) with mean number of medications at

baseline (3.58, SD 2.61 for 59 survivors vs. 4.91, SD 3.66 for 35 who died, t test $p = .064$). There were no significant differences in any other baseline characteristics between the survivors and those who died.

Table 2 goes here

Pathways

A large shift in the living situation of survivors occurred from domiciliary (87.4% at baseline) to residential care (85% of survivors at 12 months). People in care homes were fairly evenly divided between four types of facility (with/ without on-site nursing; with/ without registration for elderly mentally ill) (Table 2).

The 50 people who entered hospital from their own homes and were in a care home at six months had a worse CDR at baseline than the 11 who returned to their own homes ($n=14$, 28.0% severe; 30, 60.0% moderate; 6, 12.0% mild vs. 1, 9.1%; 6, 54.5%; 4, 36.4%: Mann Whitney U, $p=.045$). There were no significant differences in any other baseline characteristics between these groups.

Discharge process

Half of participants reported delays around hospital discharge ($n=32/56$, 57.1% of discharges to a care home; $n=5/11$, 45.5% to domiciliary locations). Most reasons related to delays in conducting assessments and finding placements. Uncertainties during the hospital stay about whether the person with dementia could return to their own home or should go to a care home (reported by 48/67, 71.6% of dyads) was associated with a longer length of stay (median 43.5, IQR 32.5 to 62.5 days vs. 37.0, 26.5 to 47.5 when no uncertainties were reported; Mann Whitney U, $p=.038$).

Utilisation and costs of health services

There were only three health services used by more than half of people with dementia at baseline: GP (used by 80, 73.4%), incontinence pads (58, 53.1%), chiropodist (56, 51.94%), of which 49 report self paying). Small numbers of people reported using other community (nurses, health care assistant, allied health professionals) and hospital (out patient, A&E, day hospital) services. Much reported utilisation was related to morbidities other than dementia (data not shown). Use of mental health services was low, although social work involvement increased in the period after the index hospitalisation (Table 3). There were 21 medical or surgical inpatient episodes reported at baseline (for the previous six months);

28 at 6 months; 24 at 12 months. Total health care costs were highest at baseline because of the index hospitalisation (Table 4).

Tables 3 and 4 go here

Utilisation and costs of social and informal care: people with dementia in domiciliary settings

At baseline, over half of people with dementia living in a domiciliary situation (49/95) reported personal care packages; 65.3% (32/49) stated that the package was fully funded by social services, the rest were full or partial self payers. Social care packages were larger for those living alone than for those living with others (Table 5).

Table 5 goes here

Regarding informal care, designated carers who were not co-resident reported providing a median of 10 hours assistance, with a further 1 hour (median) of input from other (secondary) carers. The CAS was completed by 26 co-resident carers at baseline. Analysis showed that many reported spending large proportions of a day on supervision (9 reported > 1000 minutes, 16.7 hours). As supervision may be undertaken at the same time as other activities (e.g. watching television, preparing meals), time spent on this was disregarded. Even so, five carers reported spending more than 1440 minutes (24 hours) on the five remaining components of CAS. Median time caring was 400 minutes (6 hours 40 minutes) at baseline and higher at follow-up (Table 5). Some carers (n=13) stated they had given up or cut down on work to provide care; all were sons or daughters, and in nine cases the person with dementia was living alone.

At baseline, the value of informal caring of co-resident carers is high, and the cost of social care packages is relatively low, compared to people with dementia who lived alone. Median expenditure on social care packages for the small number of people with dementia still living in a domiciliary setting at six and 12 months follow-up was higher than at baseline (Table 6). The cost of informal care at follow-up is not shown due to the small number of people for whom data are available (Table 5).

Table 6 goes here

Comparison of residential and domiciliary care packages

A cost for residential care was taken from national data because many respondents were uncertain about the care home fees, particularly when they were subsidised by public authorities. The six monthly costs of £15,132, based on the average weekly rates for private nursing and residential homes (Curtis 2010), is substantially more than the cost of domiciliary social care packages reported at baseline (median £5,016 if live alone, £0 with co-resident carer). However, the dementia rating of people in the domiciliary setting was significantly lower than that of the care home residents (Table 1), and informal caring is not included, so this is not a fair comparison. The cost of the top quartile of social care packages at six and 12 months may be equivalent to or exceed care home fees (Table 6).

When the costs of informal and social care for people who have co-resident carers at baseline are summed, the value of caring time reported through the CAS was higher than the costs of residential care. For those living alone in their own homes at baseline, the sum of informal and social care is roughly equivalent to the cost of residential care (Table 6). If the dementia severity of people in the domiciliary setting been equivalent to that in the residential setting, the cost disadvantage of domiciliary care might have been greater.

To account for the fact that care costs rise with dementia progression, the costs of 16 participants with severe dementia (CDR=3) living alone in their own homes at baseline were compared with those of care home residents with the same level of cognitive impairment (i.e. 10 of the 14 people recruited from care homes). Domiciliary care (social and informal) over six months was more costly (mean £19,315, 95% CI £12,407 to £26,223) than the national average of care home fees of £15,132, but not significantly so (indicated as the average care home fee lies within the 95% CI). Comparisons of the costs of domiciliary and residential care could not be undertaken for people with moderate dementia due to the small number of care home residents in that category.

There were 37 people with dementia who lived alone in their own homes prior to admission to hospital and were discharged to a care home. The six month social and informal caring costs of this group in the domiciliary setting (mean £18,238, 95% CI £14,262 to £22,213) were greater than the national average cost of long term care (£15,132), but not significantly so. This group contained: five people with mild dementia at baseline (CDR=1) who were graded as moderate (4) and severe (1) at six month follow up;

20 with moderate dementia at baseline (CDR=2), graded mild (1), moderate (10), severe (9) at follow up; 12 graded severe (CDR=3) at baseline, graded moderate (5), severe (6), missing (1) at follow up.

Discussion

We recruited most participants during a lengthy hospital stay, often prolonged by uncertainties about discharge destination. A combination of physical health issues and dementia resulted in high mortality (37%) over the subsequent 12 month period, and a move to residential care for the vast majority of survivors. These trends are similar to those observed by others (Hope et al 1998; Sampson et al 2009; Scocco et al 2006).

Analysis of social and informal care focussed on baseline data before recruitment to the study because few participants remained in their own homes at six and 12 month follow-up. As identified by earlier studies (O'Connor et al 1989; O'Connor et al 1991; Nelson et al 2002), social care packages were larger, and informal care input was lower, for people with dementia who lived alone, compared to those living with others, suggesting substitution between social and informal care. Co-resident carers reported high and variable caring time commitments (median nearly seven hours per day after supervision time was disregarded). Measuring carer time is problematic (McDaid 2001; Mentzakis et al 2011), but evidence collected in this study is largely consistent with the findings of others (Langa et al 2001; Schneider et al 2002; Walker et al 2006; Bonsang 2009; van den Berg et al 2006a).

For participants who remained in a domiciliary setting for the full 12 months, the cost of social care rose over time. Although this finding is based on a small sample, it is consistent with other evidence (Soutre et al 1999; Wolstenholme et al 2002, Hux et al 1998). The cost of residential care is usually greater than social care packages. However, when social and informal care costs are combined, the situation is less clear. In line with a previous study (Schneider et al 2003), the value of caring time reported by co-resident carers exceeded the cost of residential care. Considering all the people with dementia who lived alone in the sample, the cost of their social and informal care was roughly equivalent to that of residential care, but their dementia was, on average, less severe than that of care home residents. Comparing the care costs of the small numbers of people with severe dementia across settings showed that long term care was a less expensive option, but the difference was not statistically significant.

Consistent with the small sample size, the confidence intervals were wide, and a more incisive assessment might have arisen from a larger sample.

Costs of alternative scenarios need to be considered in conjunction with outcomes, and the lowest cost outcome is not necessarily the best (Challis and Hughes 2003). Care home placement is typically met with mixed emotions for carers (Penrod et al 1998; Davis and Nolan 2003; Alcock et al 2002, Authors 3), but in line with previous research (Levin et al 1989; Levin et al 1994) was associated in this study with improved psychological wellbeing, as measured by the GHQ; for the carers of 50 people with dementia who moved to a care home after hospital, GHQ improved between baseline and six (3.58 points, $p < .0005$) and 12 (4.15 points, $p < .0005$, $n=48$) month follow-up. The quality of life of people with dementia may also be affected by the care environment (deRooij et al 2012) but measuring this is problematical (Authors 1; Moyle et al 2011; Schiffczyk et al 2010). Proxy assessments provided by designated carers in this study, however, showed no changes in the quality of life of surviving people with dementia over 12 months, even though most had moved from domiciliary to care home locations (Authors 2).

The study is limited in several ways. Recruitment difficulties reduced the sample size and resulted in small numbers in subgroups. Identification of potential participants by the psychiatric liaison services, and delays around the informed consent processes, meant that people recruited were mostly those with longer hospital stays reflecting complex medical or social problems. Hence the findings may not be generalizable to people with dementia that have not been hospitalised, or had shorter hospital stays.

Although data were meticulously collected by interview, they were self-reported, and inaccuracies could have arisen from six month recall of health care use. Also, social care utilisation was only recorded over a one month period and multiplying this up to give a cost over six months may have resulted in an overestimate if the package had increased over time. Other uncertainties surround the measurement and valuing of informal care. Carers may overstate informal caring time when recall methods are used, compared to a diary (van den Berg and Spauwen 2006b). Many live-in carers reported that they spent more than 24 hours each day in caring activities, and as the extent of 'joint production' could not be identified, we removed time spent in supervision from the calculation. Although other studies have also used this approach (Schneider et al 2002), there is evidence that time spent on supervision increases as dementia progresses (Marin et al 2000), so it may have resulted in an underestimation of the costs of

informal caring. Replacement cost methods were used to value informal caring, but other methods exist, and may have given different results (McDaid 2001; van den Berg et al 2004; Mentakis et al 2011). In particular, the positive utility that some carers report they experience from the caring process is not taken into account (McDaid 2001; van den Berg et al 2004; 2005a; 2005b; 2007; de Meyer et al 2010; Brouwer et al 2005). Other uncertainties around the cost calculations arise from the large standard deviations for many categories of costs. Also, poor responses to the questions about who paid for care means that the costs do not distinguish between the contribution of the statutory authorities and private families. Closure of day centres and pressure for increasing use of direct payments make it possible that packages of social care would have changed since this study was conducted.

For people at the margins between domiciliary and long term care, factors other than relative costs, such as the existence and health of a spouse, family preferences and the availability of local services (both domiciliary and care home places) may be critical (Cohen et al 1993; Alcock et al 2002; Challis and Hughes 2002; Tucker et al 2008; Williams et al 2009). Various ways of smoothing decision making about care location have been promoted including better coordination across services (Knapp et al 2012), and enhanced roles for care managers (Koch et al 2012). Recently, the main policy thrust in the UK has been directed at providing additional support for carers to enable them to continue their caring role (HM Government 2010) at significant savings to the public sector. There is concurrently a need to ensure that high quality services are provided in both domiciliary and long term care settings (Alzheimer's Society 2008; Chenworth et al 2009; Sims Gould and Martin-Matthews 2010 ; Glendenning 2012), which is a challenge for resource-constrained agencies.

References

Achterberg W, Pot AM, Kerkstra A, Ribbe M. Depressive symptoms in newly admitted nursing home residents. *International Journal of Geriatric Psychiatry* 2006; 21(12): 1156-62

Alcock D, Angus D, Diem S, Gallagher E, Medves J. Home care of long term care facility: factors that influence the decision. *Home Health Care Service Quarterly* 2002; 21(2): 337-359

Alzheimer's Research Trust. Dementia 2010: the economic burden of dementia and associated research funding in the UK. Alzheimer's Research Trust and Health Economics Research Centre, University of Oxford, 2010

Alzheimer's Society. Home from home: quality of care of people with dementia living in care homes, 2008

Alzheimer's Society. Counting the cost: caring for people with dementia in hospital wards, 2009

Authors 1.

Authors 2.

Authors 3.

Bonsang E. Does informal care from children to their elderly parents substitute for formal care in Europe? *Journal of Health Economics* 2009; 28: 143- 154

Bosanquet N. The socio-economic impact of Alzheimer's disease. *International Journal of Geriatric Psychiatry* 2001; 16: 249-252

Brouwer WBF, van Eek NJA, van den Berg B, van den Bos GAM, Koopmanschap MA. Process utility from providing informal care: the benefit of caring. *Health Policy* 2005; 74: 85-99

Burns A. Alzheimer's disease. *British Medical Journal* 2009; 338: b158

Burvill P.W., Mowry B., Hall W.D. Scale for measuring physical illness in the elderly. *International Journal of Geriatric Psychiatry* 1990; 5: 161 - 170

Challis D, Hughes J. Frail old people at the margins of care: some recent research findings. *British Journal of Psychiatry* 2002; 18(2): 126-30

Challis D, Hughes J. Residential and nursing home care – issues of balance and quality of care. *International Journal of Geriatric Psychiatry* 2003; 18(3): 201-204

Chenworth L, King M, Jeon Y-H, Brodarty H, Steinarbury J, Norman R, Heias M, Luscombe G. Caring for Aged Dementia Care Resident Study (CADRES) of person centred care, dementia mapping and usual care in dementia: a cluster randomised trial. *The Lancet Neurology* 2009; 8(4): 317-25

Chisholm D., Knapp M.R.J., Knudsen H.C., Amaddeo F., Gaité L., van Wijngaarden R. European version: development of an instrument for international research: EPSILON study 5 Client socio-demographic and service receipt inventory. *British Journal of Psychiatry* 2000; 177:s28-s33.

Coduras A, Rabasa I, Frank A, Bermejo-Pareja F, Lopez-Pousa S, Lopez-Arrieta J-M, Llano JD, Leon T, Rejas J. Prospective one-year cost-of-illness study in a cohort of patients with dementia of Alzheimer's disease type in Spain: the ECO study. *Journal of Alzheimer's disease* 2010; 19: 601-615

Cohen CA, Pushkar Gold D, Shulman KI, Wortley JT, McDonald G, Wargon M. Factors determining the decision to institutionalise dementing individual: A prospective study. *The Gerontologist* 1993; 33: 714-720

Cowdell F. The care of older people with dementia in acute hospitals. *International Journal of Older People Nursing* 2010; 5(2): 82-92

Curtis L. Unit costs of health and social care 2010. www.pssru.ac.uk

Davies S, Nolan M. 'Making the best of things': relatives experiences of decisions about care home entry. *Aging and Society* 2003; 23: 429-50

Davis K.L., Marin D.B., Kane R., Patrick D., Peskind E.R., Raskind M.A., Puder K.L. The Caregiver Activity Survey (CAS): Development and validation of a new measure for caregivers of persons with Alzheimer's disease. *International Journal of Geriatric Psychiatry* 1997; 12: 978-988

De Rooij AHPM, Luijkx KG, Schaafsma J, Declercq AG, Emmerink PMJ, Schols JMGA. Quality of life of residents with dementia in traditional versus small-scale long-term care settings: a quasi experimental study. *International Journal of Nursing Studies* 2012; 49: 931-940

Digby R, Bloomer MJ. People with dementia and the hospital environment: the view of patients and family carers. *International Journal of Older People Nursing* 2013. Doi:10.1111/opn.12014

Folstein MF, Folstein SE, McHugh PR. 'Mini-mental state': A practical method for grading the cognitive state of patients for the clinician". *Journal of Psychiatric Research* 1975; 12 (3): 189-98.

Glendenning C. Home care in England: markets in the context of under-funding. *Health and Social Care in the Community* 2012. Doi:10.1111/j.1365-2524.2012.01059.x

Goldberg, D. P. & Williams, P. *The User's Guide to the General Health Questionnaire*. Windsor: NFER—Nelson.1988

Harrow BS, Mahoney DF, Mendlesohn AB, Ory MG, Coon DW, Belle SH, Nichols LO. Variation in cost of informal caregiving and formal service use for people with Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias* 2004; 19(5): 299-

- HM Government. Recognised, valued and supported: next steps for the Carers Strategy. 2010
- Hope T, Keene J, Gedling K, Fairburn CG, Jacoby R. Predictors of institutionalisation for people with dementia living at home with a carer. . *International Journal of Geriatric Psychiatry* 1998; 13: 682-690
- House of Commons Public Accounts Committee. *Improving services for people with dementia*, HC 228, 2008
- Hux MJ, O'Brien BJ, Iskedjian M, Goeree R, Gagnon M, Gauthier S. Relation between severity of Alzheimer's disease and costs of caring. *Canadian Medical Association Journal* 1998; 159 (5): 457-65
- Knapp M, Prince M. *Dementia UK*. The Alzheimer's Society, 2007
- Knapp M, Lemmi V, Romeo R. Dementia care costs and outcomes: a systematic review. *International Journal of Geriatric Psychiatry* 2012. Doi: 10.1002/gps.3864
- Koch T, Iliffe S, Manthorpe J, Stephens B, Fox C, Robinson L, Livingston G, Coulton S, Knapp M, Chew-Graham C, Katona C, and CARE-DEM. The potential of case management for people with dementia: a commentary. *International Journal of Geriatric Psychiatry* 2012. Doi: 10.1002/gps.2783
- Langa K, Chernow M, Kabeto MU, Herzog AR, Ofstedal MB, Willis RJ, Wallace RB, Mucha LM, Straus WL, Fendrick M. National estimates of the quantity and cost of informal caring for the elderly with dementia. *Journal of General Internal Medicine* 2001; 16: 770-8
- Lawton M.P., Brody E.M. Assessment of older people: self maintaining and instrumental activities of daily living. *Gerontologist* 1969; 9: 179-186
- Lewin E, Moriarty J, Gorbach P. *Better for the Break*. HMSO. London, 1994
- Lewin E, Sinclair I, Gorbach P. *Families, Services and Confusion in Old Age*. Ashgate Publishing, Aldershot, 1989
- Marin DB, Dugue M, Schmeidler J, Santoro J, Neugrosch J, Zakland G, Brickman A, Schnur E, Hoblyn J, Davis KI. The Caregiver Activity Survey (CAS): longitudinal validation of an instrument that measures time spent caregiving for individuals with Alzheimer's disease. *International Journal of Geriatric Psychiatry* 2000; 15: 680-686
- McDaid D. Estimating the costs of informal caring for people with Alzheimer's disease: methodological and practical challenges. *International Journal of Geriatric Psychiatry* 2001; 16 (4): 400-405
- Mecocci P, von Strauss E, Cherubini A, Ercolani S, Mariani E, Winblad B, Fratiglioni L. Cognitive impairment is the major risk factor for development of geriatric syndromes during hospitalization: results from the GIFA study. *Dementias and Geriatric Cognitive Disorders* 2005; 20(4): 262-269
- Mentakis E, Ryan M, McNamee P. Using discrete choice experiments to value informal care tasks: exploring heterogeneity. *Health Economics* 2011; 20: 930-944
- Morris J. The Clinical Dementia Rating: current version and scoring rules. *Neurology* 1993; 43: 2412 – 3

Morrison RS, Siu AL. Survival in End-Stage Dementia Following Acute Illness *Journal of the American Medical Association* 2000; 284: 47-52

Moyle W, Murfield JE, Griffiths SG, Venturato L. Assessing quality of life of older people with dementia: a comparison of quantitative self-report and proxy accounts. *Journal of Advanced Nursing* 2011; 68(10): 2237-2246

Mukadem N, Sampson EL. A systematic review of the prevalence, associations and outcomes of dementia in older general hospital inpatients. *International Psychogeriatrics* 2011; 23: 344-355

Nelson T, Livingston G, Knapp M, Manela M, Kitchen G, Katona C. Slicing the health service cake: the Islington study. *Age and Aging* 2002; 31: 445-450

O'Connor DW, Pollitt PA, Brook CPB, Reiss BB. The distribution of services demented elderly people living in the community. *International Journal of Geriatric Psychiatry* 1989; 4:339-344

O'Connor DW, Pollitt PA, Brook CPB, Reiss BB, Roth M. Does early intervention reduce the number of elderly people with dementia admitted to institutions for long term care? *British Medical Journal* 1991; 302: 871-875

Penrod J, Strang VR, Neufeld A, Nolan M. Caregivers' experiences in making placement decisions. *Western Journal of Nursing Research* 1998; 20(6): 706-32

Sampson EL, Gould V, Lee D, Blanchard MR. Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study. *Age and Aging* 2006; 35: 187-189

Sampson EL, Blanchard MR, Jones L, Tookman A, King M. Dementia in the acute hospital: prospective cohort study of prevalence and mortality. *British Journal of Psychiatry* 2009; 195: 61-66

Schiffczyk C, Romero B, Jonas C, Lahmeyer C, Muller F, Riepe MW. Generic quality of life assessment in dementia patients: a prospective cohort study. *BMC Neurology* 2010; 10:48

Schneider J, Hallam A, Murray J, Foley B, Atkin L, Banerjee S, Islam MK, Marin A. Formal and informal care for people with dementia: factors associated with service receipts. *Aging and Mental Health* 2002; 6(3): 255-263

Schneider J, Hallam A, Islam MK, Murray J, Foley B, Atkin L, Banerjee S, Marin A. Formal and informal care for people with dementia: variations in costs over time. *Aging and Society* 2003; 23: 303-326

Scocco P, Rapattoni M, Fantoni G. Nursing home institutionalisation: a source of eustress or distress for the elderly? *International Journal of Geriatric Psychiatry* 2006; 21(3): 281-287

Sims-Gould J, Martin –Matthews A. We share the care: family caregivers experiences of their older relative receiving home support services. *Health and Social Care in the Community* 2010; 18(4): 415-423

- Souetre E, Thwaites RMA, Yeardley HL. Economic impact of Alzheimer's disease in the UK. *British Journal of Psychiatry*
- Trabucchi M. An economic perspective on Alzheimer's disease. *Journal of Geriatric Psychiatry and Neurology* 1999; 12: 29-38
- Tucker S, Hughes J, Burns A, Challis D. The balance of care: reconfiguring services for older people with mental health problems. *Aging and Mental Health* 2008; 12(1): 81-91
- van den Berg B, Brouwer W, Koopmanschap M. Economic valuation of informal care. *European Journal of Health Economics* 2004; 5: 36-45
- van den Berg B, Brouwer W, van Exel J, Koopmanschap M. Economic valuation of informal care: the contingent valuation method applied to informal caregivers. *Health Economics* 2005a; 14: 169-183
- van den Berg B, Bleichrodt H, Exckhoudt L. Economic valuation of informal care: a study of informal caregivers' and patients' willingness to pay and willingness to accept for informal care. *Health Economics* 2005b; 14: 363-376
- van den Berg B, Brouwer W, van Exel J, Koopmanschap M, van den Bos GAM, Rutten F. Economic valuation of informal care: lessons from the application of the opportunity costs of proxy good methods. *Social Science and Medicine* 2006a; 62: 835-845
- van den Berg B, Spauwen P. Measurement of informal care: an empirical study into the valid measurement of time spent on informal caring. *Health Economics* 2006b; 15: 447-460
- van den Berg B, Ferrier-i-Carbonell A. Monetary valuation of informal care: the wellbeing valuation method. *Health Economics* 2007; 16: 1227-1244
- Walker AE, Livingstone G, Cooper CA, Katona CLE, Kitchen GL. Caregiver's experience of risk in dementia: the LASER-AD study. *Aging and Mental Health* 2006; 10(5): 532-538
- Williams AP, Challis D, Deber R, Watkins J, Kuluski K, Lum JM, Daub S. Balancing institutional and community-based care: why some older people can age successfully at home while others require residential long-term care. *Healthcare Quarterly* 2009; 12(2): 95-105
- Wolstenholme J, Fenn P, Gray A, Keen J, Jacoby R, Hope T. Estimating the relationship between disease progression and cost of care in dementia. *British Journal of Psychiatry* 2002; 181: 36-42

Table 1: Baseline characteristics of 109 people with dementia (PwD) and designated carers

Variable	Category	Living situation of person with dementia prior to admission to hospital								Significant differences		
		Care home (1)		Domiciliary live alone (2)		Domiciliary live with designated carer (3)		Domiciliary live with other (not designated carer) (4)		Care home vs. all domiciliary (1 vs.2,3,4)	Domiciliary alone vs. not alone (2 vs. 3,4)	Test
		N=14 (12.8%)		N=63 (57.8)		N = 28 (25.7)		N=4 (3.7)				
		n	%	n	%	n	%	n	%			
Gender of PwD	Male	5	35.7	13	20.6	8	28.6	1	25.0	.310	.413	Chi Sq
Gender of carer	Male	9	64.3	32	50.8	15	53.6	2	50.0	.374	.830	Chi Sq
Carer relation to PwD	Spouse	2	14.3	0		17	60.7	0		.852	<.0005	Chi Sq
	Other relative	11	78.6	59	93.6	11	39.3	4	100.0			
	Friend, other	1	7.1	4	6.4	0		0				
Carer employed (vs. not employed)	Full or part time	5	35.7	29	46.0	7	25.0	2	50.0	.759	.092	Chi Sq
		Mean (SD) Range		Mean (SD) Range		Mean (SD) Range		Mean (SD) Range				
Age of PwD	Years	88.4 (6.18) 75 - 99		85.9 (5.48) 69 - 97		83.5 (6.15) 73 - 98		81.7 (9.03) 74 - 91		.055	.040	T test
Age of carer	Years	64.5 (7.18) 51 - 83		57.93 (9.28) 29 - 78		69.93 (14.95) 43 - 90		60.69 (10.42) 52 - 72		.393	<.0005	T test
Clinical Dementia Rating (PwD)*	1 mild to 3 severe	2.7 (0.47) 2 - 3		2.06 (0.68) 0.5 - 3		1.95 (0.55) 0.5 - 3		2.0 (0) 2 - 2		<.0005	.433	Mann Whitney
MMSE (PwD) Range 0 -30	<=9 severe, >=25 normal	8.0 (4.36) 5 - 13 (n=3)		13.93 (4.87) 5 - 23 (n=40)		13.38 (5.22) 5 - 23 (n=13)		13.0 (0) 13 - 13 (n=1)		.049	.711	T test
IADL (PwD) Range 0 - 8	Low is dependent	0.14 (0.36) 0 - 1		1.98 (1.91) 0 - 8		1.57 (1.64) 0 - 8		1.0 (1.41) 0 - 3		<.0005	.258	T test
Carer GHQ Range 0 - 36	0 good - 36 high stress	13.02 (5.03) 3.27 - 21.0		16.70 (6.26) 6 - 36		15.39 (6.30) 7 - 36		14.0 (4.83) 10 - 21		.070	.275	T test
Length of index hospital stay	Days	47.4 (31.0) 19 - 139		47.4 (29.0) 4 - 136		49.6 (34.4) 9 - 161		44.7 (8.1) 31 - 50		.966	.844	T test

Key: MMSE = Mini Mental State Examination; IADL = Instrumental Activities of Daily Living; GHQ = General Health Questionnaire

* Care home: 10 severe, 4 moderate; Live alone: 16 severe, 35 moderate, 12 mild; Live with designated carer: 3 severe, 21 moderate, 4 mild; Live with others, not designated carer: 4 moderate.

Table 2: Participant pathways

Place of residence	Place of residence prior to recruitment in hospital, n (% of total)	Between baseline and 6 month follow up		Place of residence at 6 month follow up, n (% of total)	Between 6 and 12 month follow up		Place of residence at 12 month follow up, n (% of total)
		Died	Withdrew/lost to follow up		Died	Withdrew/lost to follow up	
Care home / residential care	14 (12.8)	8	0	56 (83.6)	5	0	51 (85.0) #
Domiciliary alone	63 (57.8)	14	4	11 (16.4)	2	0	9 (15.0)
Domiciliary with designated carer/ other	32 (29.4)	11	5				
TOTAL	109	33*	9	67	7	0	60
Total as % those recruited	100.0	30.3	8.3	61.5	6.4	0	55.0
<p>* 7 people died in hospital # All participants were in different care homes: n=11 (21.6%) in care homes without nursing; 15 (29.4%) in care homes with on-site nursing; 14 (27.4%) in EMI homes (Elderly Mentally Ill) without nursing; 11 (21.6%) EMI with on-site nursing.</p>							

Table 3: Utilisation of mental health services

Mental health service	Number (%) of people with dementia accessing each service		
	Baseline, covering the 6 months prior to recruitment (N=109*)	6 months between hospital discharge and 6 month follow up (N=67)	6 months between 6 month and 12 month follow up (N=60)
Psychiatric inpatient stays	n=2 living alone:1 admission each (1 + 5 days) n=1 live own home, not alone: 2 admissions (90 days total)	2 people live own homes each with 1 admission of 15 days	None
Psychiatric outpatient	n=18 (16.5%)	n= 10 (14.9%)	n= 9 (15.0%)
Community psychiatrist	n=14 (12.8%)	n= 5 (7.5%)	n= 6 (10.0%)
Community mental health nurse	n=17 (15.6%)	n= 13 (19.4%)	n= 7 (11.7%)
Social worker/ care manager	n=32 (29.4%)	n=29 (43.2%)	n=17 (28.3%)
* Dementia was not diagnosed in 23 of the 109 participants until the hospital stay			

Table 4: Summary (median, IQR) of per participant costs of health service utilisation* (£, 2010): in last 6 months (baseline); since last interview, i.e. approximately 6 months, at 6 and 12 month follow-up

Median (IQR)	Baseline (N=109)			6 month follow up (N=67)		12 month follow up (N=60)	
	Domiciliary Live alone	Domiciliary with designated carer/other	Care home	Domiciliary	Care home	Domiciliary	Care home
	n=63	n=32	n=14	n=11	n=56	n=9	n=51
Total hospital (in and out patient, day hospital, A&E)	15120 (10576 - 21960)	14405 (11024 - 248642)	17834 (13789 - 25580)	0 (0 - 3049)	476 (0 - 4029)	0 (0 - 950)	136 (0 - 496)
Total community (GP, psychiatrist, nursing, allied professionals, social worker, continence supplies)	284 (148-573)	248 (185-498)	406 (0-1600)	371 (297-435)	412 (181-717)	227 (143-373)	470 (204-774)
Total health care	15289 (11149-22136)	16432 (12317-25379)	18611 (14023-27310)	590 (347-3486)	1542 (511-4662)	363 (222-1086)	789 (345-1539)
* Excludes any self paid services, and medications							

Table 5: Utilisation of social and informal care, per month: people with dementia living in a domiciliary setting only

SERVICE: Number of people receiving service; (Median, IQR of contacts)		Baseline, previous month pre hospitalised			6 month follow up *	12 month follow up *
		Live alone	Live with designated carer	Live with other		
		N=63	N=28	N=4		
Personal care **		n= 36 (61 responded) (30, 0 – 76)	n=11 (27 responded) (0, 0 – 28)	n=2 (46, 0 – 94)	n=11 (66, 0 – 113)	n=5 (68, 0 – 174)
Home help		n= 23 (61 responded) (0, 0 – 4)	n=5 (27 responded) 0, 0 – 0 (n=27)	n=0 0, 0 - 0	n=3 0, 0 - 3	n=3 0, 0 - 3.75
Transport / dial a ride (number)		0	0	0	n=1 (24 rides/month)	0
Home meals (number)		n=13 0, 0 - 0	n=2 0, 0 - 0	n=0 0, 0 - 0	n=1 0, 0 - 0	n=3 0, 0 - 0
Day care centre (days per week)		n=10 0, 0-0	n=5 0, 0 - 0	n=1 0, 0 - 2.25	n=0 0	n=0 0
Informal care (hours per week) by designated carer		n=40 (43 responded) 10, 4 – 18	Not relevant	n=1 (3 responded) 0, 0 – 0	n=7 9, 2.25 – 17	n=6 5, 2-18
Care by person other than designated carer (hours in average week)		n= 34 (61 responded) 1, 0 - 6.5	n=10 0, 0 - 6.25	n=2 (3 responded) 0, 0 - 3.33 (n=3)	n=5 0, 0 - 7	n=4 0, 0 - 8.5
Informal care by designated carer, minutes per day, from Caregiver Activity Survey (CAS) #	Category of care	Not relevant	n=26 responded Range of minutes /day	Not relevant	n=1 responded Minutes per day	n=3 responded Minutes per day
	Communication		0 (n=3) - 1440		300	0,300,600
	Transport		0 (n=16) - 120		0	0,0,0
	Dressing		0 (n=8) - 960		60	0,5,60
	Eating		0 (n=10) - 360		120	120,180,210
	Grooming		0 (n=11) - 240		120	15,30,60
	Total		0 (n=1) – 3360 Median 400 minutes		1440 Median 1440 minutes	135 – 930 Median 515 minutes
* 'Since we last saw you' i.e. since last interview, approximately 6 months, then standardised to monthly (i.e. divide by 6).						
** Payer, n= 49, baseline: self (full or part) 17; social services 32						
#Caregiver Activity Survey (Davis et al 1997; Marin et al 2000); supervision time excluded and still the sum of remaining 5 categories > 1440 minutes (1 day) for 5 carers						
Note: no participants reported any paid carers.						

Table 6: Social and informal care costs per participant (£,2010), monthly data converted to six monthly to cover six months prior to each data collection point: people living in a domiciliary situation only

Living situation (all domiciliary)	Baseline					6 month follow up		12 month follow up	
	Mean (SD)					Mean (SD)		Mean (SD)	
	Median (IQR)					Median (IQR)		Median (IQR)	
	N	Social care*	Main informal carer	Other informal care	Total social and all informal care	N	Social care*	N	Social care*
Live alone	63	6,774 (7,656) 5,016 (0 – 11,040)	5,966 (7,960) 2,704 (0 – 9,466)	2,629 (5,033) 676 (0 – 4,056)	15,369 (11,709) 13,500 (7,098 – 23,424)	11	9,709 (10,519) 7,980 (0 – 14,080)	9	10,727 (11,497) 8,160 (0 – 21,300)
Live with designated carer	28	3,214 (5,399) 0 (0 – 4,578)	N/A Median 26,936#	4,466 (14,422) 0 (0 – 4,225)	N/A				
Live with other (not designated carer)	4	6,312 (5,782) 6,984 (702 – 11,250)	2,535 (3,236) 1,690 (0 – 5,915)	1,690 (3,380) 0 (0 – 5,070)	7,681 (15,124) 1,612 (0 – 10,946)				
* Social care includes personal care, home help, travel, meals, day care; costs include payment by individuals and by formal services # Estimate based on Caregiver Activity Survey median of 400 minutes per day caring and applying Local Authority home care worker hourly rate									