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ORIGINAL ARTICLE

Do general practitioners disclose correct information to their patients suspected of dementia and their caregivers? A prospective observational study

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Abstract

This study describes what general practitioners (GPs) tell persons who appear to have dementia and their caregivers after assessment and to estimate the number of (in)correct disclosures and their determinants. In a prospective observational study 64 GPs were instructed to use the Dutch national dementia guideline on all consecutive elderly (55+) patients, newly suspected of dementia. Patients were referred to a multi-disciplinary memory clinic team that served as a diagnostic reference standard. Both GPs and the memory clinic team registered their findings and actions on a predefined form. A total of 107 possible cases of dementia were recorded, and 83 were accompanied by their caregiver. After assessment, dementia was considered present in 69 persons, absent in 29, and uncertain in nine. The GPs told the diagnosis to 42% of people with probable dementia and to 74% of their caregivers. The caregivers' experiences were noted in most cases but specific advice was provided in less than half. Only increased severity of dementia was related to more disclosure to patients and caregivers. Disclosures by GPs were correct in most cases. The GPs were much more reluctant to tell the probable dementia diagnosis to patients than to (family) caregivers. The GPs disclosed incorrect diagnoses to two people without dementia, and two with dementia according to the memory clinic diagnosis.

Introduction

The general practitioner (GP) is often the first physician to see and assess patients with possible dementia, but we remain unaware of what GPs tell patients and their family caregivers. Many physicians are unnerved at the prospect of revealing a dementia diagnosis to a patient (Vassilas & Donaldson, 1998), this may be due to uncertainty about the risks and benefits of early diagnosis, diagnostic uncertainty, and embarrassment to test and tell (Iliffe et al., 2003; Keightley & Mitchell, 2004; Renshaw et al., 2001; van Hout et al., 2000). Note that old-age psychiatrists, geriatricians in the UK, reported comparable reluctance to tell patients they suffer from dementia (Johnson et al., 2000; Hertogh et al., 2004).

Many professionals working with persons with dementia experience an ambivalence to withhold the diagnosis from patients but tell (family) caregivers. Possible negative consequences of disclosure are the potential stigmatization of patients and the fact that patients have to come to terms with the diagnosis of a devastating disease. There are case-reports of depression, suicidal intent and even suicide after

disclosure (Rohde et al., 1995). Arguments that favour telling the diagnosis include the right to know, enabling patients and caregivers to better understand and deal with changed behaviour, permitting patients and caregivers to prepare future care planning, and allowing support for the often severely burdened caregivers (Drickamer & Lachs, 1992; Meyers, 1997).

A study among elderly patients in a general practice waiting room reported that 92% wished to know a 'hypothetical' diagnosis of dementia (Erde et al., 1988). Two studies among memory clinic attenders reported that most (67 and 96% respectively) wanted to know what was wrong (Marzanski, 2000; Dautzenberg et al., 2003). Irish (17%) and Italian caregivers (40%) may be much more reluctant to tell the patient the diagnosis compared to English (84%) and Dutch (100%) carers (Dautzenberg et al., 2003; Maguire, 2002; Pucci et al., 2003; Smith et al., 1998). Most people with dementia found it helpful (98%) to have it disclosed to them (Smith et al., 1998).

This study was designed to describe what GPs tell patients with possible dementia and their caregivers, to estimate the number of (in)correct disclosures, and to examine which factors determine the GPs' decision to disclose or withhold a diagnosis.

Methods

Subjects and design

A group of GPs from the eastern part of the Netherlands were recruited to participate in an observational study. The GPs were asked to use the dementia guideline of the Dutch College of General Practitioners (DCGP) to assess, diagnose and inform consecutive newly suspected patients who were: (1) 55 years or older; and (2) showed signs of cognitive impairment. All these patients were referred to a memory clinic. The medical ethics committee of the University Hospital St. Radboud approved the study.

Dementia guideline

The Dutch dementia guideline was established as part of a guideline-setting program of the DCGP and the first edition was already issued in 1991 and the first update was issued in 1999 (De Bruyne et al., 1991; Wind et al., 1999). The dementia guideline closely resembles the American guidelines of the Agency for Health Care Policy and Research (AHCPR) and of the Veteran Affairs as well as the North England dementia guideline for primary care (van Hout et al., 2002; Eccles et al., 1998). It uses the diagnostic criteria of the Diagnostic Statistical Manual of Mental Disorders (DSM; American Psychiatric Association, 1994) and comprises recommendations for assessment of cognitive and physical functioning, and activities of daily living (ADL). A cognitive screening test such as the Mini-Mental State Examination (MMSE; Folstein et al., 1975) is optional. Instead, the dementia guideline included a brief assessment of 11 cognitive functions that correspond to the DSM-III-R criteria (long- and short-term memory; orientation to time, place, and person; gnosis; praxis; language ability; judgment; personality changes; and abstraction), and indications on how to assess these functions.

Measurements

A registration form was made that closely mirrored the recommendations of the dementia guideline. For every diagnosed patient the GPs completed this registration form on which they indicated their actions, assessment findings, whether a close caregiver was available, the presence of dementia (yes, no, uncertain), disclosure and issues discussed with caregivers. The following clinical features were recorded: cognitive functions were scored as normal, impaired or uncertain. The level of ADL

dependency of a patient was scored on a four-point Likert scale ranging from independent to severely dependent. For cognitive symptoms a sum score was computed to reduce the number of variables. A sum score of the 11 cognitive functions was made (long- and short-term memory; orientation to time, place, and person; gnosis; praxis; language ability; judgment; personality changes; and abstraction) (Cronbach's $\alpha = 0.75$).

Regarding the GP's performance the following variables were recorded: the number of contacts needed, whether a home visit was done, MMSE used, the need to refer, and the total number of recommendations from the guideline, which was expressed as a sum score from a list of 31 possible recommendations (Cronbach's $\alpha = 0.76$). Two indicators for continuity of care, namely the length and familiarity of the GP-patient relationship, were recorded by the GP on a four-point Likert scale.

Reference standard: Memory clinic

An experienced multidisciplinary team that involved a geriatrician, a neurologist and a psychologist, assessed the presence of dementia in all suspected referred patients. To this aim, the CAMDEX (Cambridge Mental Disorders of the Elderly Examination) and the criteria of the DSM-IV were used (Roth, 1986; American Psychiatric Association, 1994). The assessment, interpretation and communication of the results took approximately 4.5 hours spread over three visits. The memory clinic's team was blinded to the GPs' diagnoses.

Variables associated with telling the diagnosis

We explored whether telling was associated with: (1) clinical features such as ADL dependency, time since onset of symptoms and denial of cognitive impairment (denial was considered to possibly complicate the GP's assessment procedure); (2) the demographics of GPs and patients; (3) performance of the GP such as the number of assessment contacts, use of the MMSE and the need of the GP for a diagnostic referral; and (4) two continuity of care indicators (length and familiarity of the GP-patient relationship).

Analyses

Descriptive statistics were used to report on what information was told to patients and caregivers and to compare this to the GPs and memory clinic diagnoses. Univariate logistic regression analyses were used to investigate which demographic and clinical variables were associated to telling. Therefore, the GPs' diagnoses were dichotomized into dementia present or absent. We choose to classify the nine cases with GPs' diagnoses 'unsure' as dementia absent as the DCGP guideline recommends a reluctant policy in such cases. In sensitivity

analyses we checked whether another classification changed the findings. This was not the case. Finally, multivariate logistic analyses were performed with the significant univariate associations with telling to check whether they remained significant.

Results

Subjects GPs, patients and family caregivers

The 64 GPs participating assessed and registered 107 patients with cognitive impairment, a mean of 1.7 patients per GP during the average participation time of 16 months. The GPs were comparable to the Dutch GP population regarding age (mean = 45 years, SD = 8), practice experience (mean = 15 years, SD = 7), practice size (mean = 2114 patients, SD = 404) and gender (21% females). There were fewer single-handed practices in the study (32% versus 49% nationwide; Harmsen & Hingstman, 1996).

Of the patients 61% were married, 87% lived independently at home, 10% in a service flat or elderly adapted home and 3% in a retirement home. A family caregiver accompanied 83 of the 107 patients. They were partner (77%), (step)child (19%), brother, sister, neighbour or nun (4%).

For 93 patients both the GPs and the memory clinic completed the diagnostic evaluation. The memory clinic team could not assess 14 patients by because of refusal (nine), medical complication (three), or death (two). The clinical and demographic characteristics of these 14 patients were comparable to the 93 patients with completed referrals.

Assessment

A diagnostic assessment by the GP required on average 3.5 consultations (SD = 8, range 1–24) and 42% of the patients were visited at home at least once. The average application rate of the Dutch dementia guideline's 31 diagnostic key recommendations was 86% or 24.8 (SD = 3.6). Assessment of abstractive ability was the least examined recommendation (70%). The Mini

Mental Status Examination, which is only optional in the Dutch guideline, was used in 17 patients (18%). Detailed information on applicability of the recommendations is reported elsewhere (van Hout et al., 2001).

Disclosures by GPs

When the GPs diagnosed the presence of dementia ($n = 69$) 42.0% of the patients and 82.3% of the caregivers were told (Table I). In these cases, less than half of the caregivers were advised on typical behavioural and communication issues in dementia (Table I).

The GPs correctly disclosed 33 out of 37 diagnoses to patients and 54 out of 61 diagnoses to caregivers. Dementia was incorrectly disclosed to two out of 10 false-positively diagnosed persons (one had depression and one had psychosis at the memory clinic assessment) (Figure 1). Absence of dementia was incorrectly told to two out of four false-negative diagnoses (both had Alzheimer's disease according to the memory clinic). To caregivers, the GPs incorrectly disclosed dementia to five out of ten false-positively diagnosed persons. Absence of dementia was incorrectly told to two out of four false-negatively diagnosed persons. The memory clinic diagnosed dementia in two of the nine persons the GPs were uncertain of.

Associations with disclosure

The severity of the cognitive impairment was (positively) associated to disclosure to both patient (OR = 3.0; 95% CI, 1.3–6.6) and caregivers (OR = 7.0; 95% CI, 2.1–24.0). Disclosure to caregivers was associated with increased number of cognitive symptoms, severity, ADL dependency and diagnostic certainty. Disclosure to patients was further only associated to GPs who worked in duo or group practices (compared to single-handed practices) (OR = 3.8; 95% CI, 1.2–12.6). None of the other variables were associated (characteristics of patients, caregivers or GPs, frequency of GP-patients contacts, clinical performance of the GPs such as using the MMSE, assessment of

Table I. Information by GPs to suspected patients ($n = 107$) and their caregivers ($n = 83$), according to the presence of dementia according to the GP.

	Demented $n = 69$	Unsure*/Not demented $n = 38$	All patients $n = 107$
Told diagnosis to patient n (%)	29 (42.0)	8 (21.1)	37 (34.6)
<i>Points to discuss with caregivers only:</i>	<i>Caregivers $n = 62$</i>	<i>Caregivers $n = 21$</i>	<i>Caregivers $n = 83$</i>
Told diagnosis to caregiver n (%)	51 (82.3)	10 (47.6)	61 (73.5)
Asked for care-giving experiences? n (%)	51 (82.3)	11 (57.9)	62 (74.7)
Noted heavy care-giving burden? n (%)	33 (53.2)	5 (23.8)	38 (45.8)
Noted ineffectiveness of continuous corrections? n (%)	29 (42.0)	3 (14.3)	32 (38.6)
Gave information on behavioural changes n (%)	24 (38.7)	3 (7.9)	27 (32.5)
Gave advice on safety issues? n (%)	24 (38.7)	1 (2.6)	25 (30.1)
Noted danger of isolation? n (%)	21 (33.9)	3 (7.9)	24 (28.9)

*Unsure concerned nine patients.

Figure 1. Flow chart of diagnoses and disclosures of GPs to patients and caregivers compared to the memory clinic's diagnoses.

cognitive functions, or other clinical features such as denial of patients, duration of the symptoms). In multivariate analyses the associations with disclosure to patients (severity, GP in group practice) remained significant (OR = 3; 95% CI, 1.3–7.1), respectively (OR = 2.3; 95% CI, 1.2–4.6). With regard to telling to caregivers, only severity remained significantly associated (OR = 6.8; 95% CI, 1.7–27.5).

Discussion

This is the first study to report disclosure figures for patients/caregivers and the number of false-negative and false-positive disclosures. Patients were assessed in accordance with the Dutch dementia guideline for GPs, but although disclosures by GPs were correct in most cases, GPs were much more reluctant to tell the probable dementia diagnosis to patients compared to caregivers. Specific advice for caregivers was provided in less than half of the cases. In multivariate analyses only severity of dementia was positively associated with disclosure both to patients and caregivers.

Strengths and limitations

The main strengths of this study were its prospective design, the detailed registration and the diagnostic comparison with the best available reference standard—a memory clinic. Also the patients were assessed in accordance with the Dutch dementia guideline, which standardized the clinical practice considerably. Although patient selection by the GPs was possible, the mean expected incidence was 1.6 patients per 2000 persons per year, while we found 1.4 patients per 2000 persons (Eccles et al., 1998). This offers only very little space for selection

bias of patients. Secondly, one can argue that it remains unclear how the diagnoses were told. It is possible that GPs, who stated they disclosed the diagnosis, actually used concealed terms such as memory problems or old age problems. Nevertheless, self-assessment measures in family practice provide valid information on medical actions (Spies et al., 2004). Last, it is possible that GPs planned to touch upon specific care-giving issues in future contacts. Also, some GPs might have assumed that disclosure issues would be covered at the memory clinic. Current figures might therefore underestimate the GPs' performance.

Several studies of GPs reported a reluctant attitude to disclose a diagnosis of dementia to patients (Vassilas & Donaldson, 1998; Iliffe et al., 2003; Renshaw et al., 2001; Downs et al., 2002). Also studies among family caregivers reported GPs reluctance to diagnose or refer (Fortinsky et al., 1995; Knopman et al., 2000). Possible explanations of the low disclosure rate to patients are reticence on the part of the GP, or the idea that (probable dementia) patients are not able to grasp the meaning of the message (Vassilas & Donaldson, 1998; van Hout et al., 2000). When efforts are undertaken to educate GPs they are much more likely to believe in the value of early diagnosis (Renshaw et al., 2001). Only a very few patients and caregivers received a false-positive or false-negative diagnosis and it is not clear what the (negative) impact was.

This study clearly showed the ambivalent approach of GPs to disclose patients on the one hand and caregivers on the other. It is unclear why most patients were left ignorant while most caregivers were not. To understand the dynamics of consultations in greater detail would require a qualitative approach, not one based on self-report

and future research should focus on interviews with GPs on whether and why a diagnosis was disclosed or withheld. A potential problem concerns the disclosure to those with a false-positive diagnosis. Unjust disclosure of dementia may not be harmless (Rohde et al., 1995). One could argue that better use of the MMSE may prevent some false positive diagnoses but in an earlier study we showed that the accuracy of the GPs' diagnoses was not associated with the use of the MMSE (van Hout et al., 1999; van Hout et al., 2002). In our study only assessment of ADL and the presence of an informant were associated with better accuracy.

The best practice regarding diagnosis disclosure to people with dementia and their caregivers remains to be established. This includes what people with dementia are told and what support is made available to those who have been told. The presented data suggest that more can be done to inform caregivers and patients on specific issues.

References

- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders (DSM-IV)*. Washington, DC: American Psychiatric Association.
- Dautzenberg, P. L., van Marum, R. J., van Der Hammen, R., & Paling, H. A. (2003). Patients and families desire a patient to be told the diagnosis of dementia: A survey by questionnaire on a Dutch memory clinic. *International Journal of Geriatric Psychiatry*, 18(9), 777–779.
- De Bruyne, G. M., Meyboom-de Jong, B., Muskens, J. B., Weytens, J. T. N. M., & Wind, A. W. (1991). De NHG-standaard dementiesyndroom [Guideline on dementia of the Dutch College of General Practitioners]. *Huisarts & Wetenschap*, 34(13), 598–607.
- Downs, M., Clibbens, R., Rae, C., Cook, A., & Woods, R. (2002). What do general practitioners tell people with dementia and their families about the conditions? A survey of experiences in Scotland. *Dementia*, 1(1), 47–58.
- Drickamer, M. A., & Lachs, M. S. (1992). Should patients with Alzheimer's disease be told their diagnosis? *New England Journal of Medicine*, 326(14), 947–951.
- Eccles, M., Clarke, J., Livingstone, M., Freemantle, N., & Mason, J. (1998). North of England evidence based guideline development project: Guideline for primary care management of dementia. *British Medical Journal*, 317, 802–808.
- Erde, E. L., Nadal, E. C., & Scholl, T. O. (1988). On truth telling and the diagnosis of Alzheimer's disease. *Journal of Family Practice*, 26, 401–406.
- Folstein, M. L., Folstein, S. E., & McHugh, P. R. (1975). Mini Mental State: A practical method for grading the cognitive status of patients for the clinician. *Journal of Psychiatric Research*, 12, 189–198.
- Fortinsky, R. H., Leighton, A., & Wasson, J. H. (1995). Primary care physicians diagnostic, management, and referral practices for older persons and families affected by dementia. *Research on Aging*, 17(2), 124–148.
- Harmsen, J., & Hingstman, L. (1996). Cijfers uit de registratie van huisartsen, peiling 1996 (Numbers of the registration of General Practitioners in the Netherlands). Utrecht: NIVEL.
- Hertogh, C. M. P. M., Anne Mei The, B., Miesen, B. M. L., & Eefsting, J. A. (2004). Truth telling and truthfulness in the care for patients with advanced dementia: An ethnographic study in Dutch nursing homes. *Social Science & Medicine*, 59(8), 1685–1693.
- Iliffe, S., Manthorpe, J., & Eden, A. (2003). Sooner or later? Issues in the early diagnosis of dementia in general practice: A qualitative study. *Journal of Family Practice*, 20(4), 376–381.
- Johnson, H., Bouman, W. P., & Pinner, G. (2000). On telling the truth in Alzheimer's disease: A pilot study of current practice and attitudes. *International Psychogeriatrics*, 12(2), 221–229.
- Keightley, J., & Mitchell, A. (2004). What factors influence mental health professionals when deciding whether or not to share a diagnosis of dementia with the person? *Aging & Mental Health*, 8(1), 13–20.
- Knopman, D., Donohue, J. A., & Guterman, E. M. (2000). Patterns of care in the early stages of Alzheimer's disease: Impediments to timely diagnosis. *Journal of the American Geriatric Society*, 48(3), 300–304.
- Maguire, C. P. (2002). Telling the diagnosis of dementia: Consider each patient individually. *International Psychogeriatrics*, 14(2), 123–126.
- Marzanski, M. (2000). Would you like to know what is wrong with you? On telling the truth to patients with dementia. *Journal of Medical Ethics*, 26(2), 108–113.
- Meyers, B. S. (1997). Telling patients they have Alzheimer's disease. *British Medical Journal*, 314(7077), 321–322.
- Pucci, E., Belardinelli, N., Borsetti, G., & Giuliani, G. (2003). Relatives' attitudes towards informing patients about the diagnosis of Alzheimer's disease. *Journal of Medical Ethics*, 29(1), 51–54.
- Renshaw, J., Scurfield, P., Cloke, L., & Orrell, M. (2001). General practitioners' views on the early diagnosis of dementia. *British Journal of General Practice*, 51(462), 37–38.
- Rohde, K., Peskind, E. R., Raskind, M. A., Post, S. G., Rubio, A., Vestner, A. L., et al. (1995). Suicide in two patients with Alzheimer's disease. *Journal of the American Geriatric Society*, 43(2), 187–189.
- Roth, M., Tym, E., Mountjoy, C. Q., Huppert, F. A., Hendrie, H., Verma, S., & Goddard, R. (1986). CAMDEX. A standardised instrument for the diagnosis of mental disorder in the elderly with special reference to the early detection of dementia. *British Journal of Psychiatry*, 149(Dec.), 698–709.
- Smith, A., King, E., Hindley, N., Barnettson, L., Barton, J., & Jobst, K. (1998). The experience of research participation and the value of diagnosis in dementia: Implications for practice. *Journal of Mental Health*, 7, 309–321.
- Spies, T. H., Mokink, H. G., De Vries Robbe, P. F., & Grol, R. P. (2004). Which data source in clinical performance assessment? A pilot study comparing self-recording with patient records and observation. *International Journal for Quality in Health Care*, 16(1), 65–72.
- van Hout, H. P. J., Vernooij-Dassen, H., Hoefnagels, W. H. L., & Grol, R. P. T. M. (1999). Use of the Mini Mental Status Examination by GPs to diagnose dementia may be unnecessary. *British Medical Journal*, 319, 190.
- van Hout, H. P. J., Vernooij-Dassen, M., Bakker, K., Blom, M., & Grol, R. (2000). General practitioners on dementia: Tasks, practices and obstacles. *Patient Education & Counselling*, 39(2–3), 219–225.
- van Hout, H. P. J., Vernooij-Dassen, M. J., Hoefnagels, W. H., Kuin, Y., Stalman, W. A., Moons, K. G., et al. (2002). Dementia: Predictors of diagnostic accuracy and the contribution of diagnostic recommendations. *Journal of Family Practice*, 51(8), 693–699.
- van Hout, H. P. J., Vernooij-Dassen, M. J. F. J., Poels, P. J. E., Hoefnagels, W. H. L., & Grol, R. P. T. M. (2001). Applicability of diagnostic recommendations on dementia in family practice. *International Journal for Quality in Health Care*, 13(2), 127–133.
- Vassilas, C., & Donaldson, J. (1998). Telling the truth: What do general practitioners say to patients with dementia or terminal cancer? *British Journal of General Practice*, 48, 1081–1082.
- Wind, A., Muskens, J., De Bruyne, G., Meijboom-de Jong, B., Weijtens, J., Burger, J., et al. (1999). NHG-standaard M21 Dementie [Dutch dementia guideline]. Utrecht: Nederlands Huisartsen Genootschap.