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A systematic literature review

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ORIGINAL ARTICLE

What is the role of the general practitioner towards the family caregiver of a community-dwelling demented relative?

A systematic literature review

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Abstract

Objective. To identify the attitudes and perspectives of the family physician towards the caregivers of demented relatives and to describe the caregivers' satisfaction. **Design.** Systematic review. **Subjects.** The studied population consisted of dementia family and their general practitioners. **Main outcome measures.** Outcome measures were the generic tasks and skills of the general practitioner to improve home care from the perspective of the family caregiver. Caregivers were assessed on satisfaction regarding the care provided by their general practitioner. **Results.** The general practitioner is aware of his/her skills and limits in all aspects of dementia care and his/her role towards the family caregiver. They also acknowledged the importance of an adequate diagnostic process, but they felt uncomfortable disclosing the diagnosis to both the patient and the caregiver. They reported having more confidence in treatment matters than in diagnostic stages. Caregivers' reports on the attitude of their general practitioner in the diagnostic process were rated from helpful to poorly empathized. General practitioners found themselves to be highly involved in dementia home care, but caregivers rated their involvement to be insufficient. The lack of appropriate communication skills of general practitioners was also not appreciated by the caregivers. A lack of time and reward was considered by the general practitioner to be a major obstacle in dementia care. **Conclusion.** The key role of general practitioners as care providers and care planners is consolidated by the family caregivers' confidence in their skills. Clear guidelines from early diagnosis to adequate referrals should improve the ability of the general practitioner to support these time and energy-consuming home-care situations. Intervention studies addressing the gaps in the skills of the general practitioners in dementia home care management could be helpful in supporting the family caregiver.

Key Words: *Dementia, family physician, family practice, general practice, general practitioner*

Taking care of a community-dwelling, demented, elderly relative places a heavy burden on the general health of caregivers [1], who tend to report a significantly higher prevalence of depression and burden than the caregivers of other chronically ill relatives and non-caregivers [1–3]. Furthermore, the burden and depression experienced by caregivers generally develop independently of the objective care need of the demented patient and are mainly evoked in poorly coping caregivers [4–6]. In addition, the successful continuation of the care situation seems to depend in particular on the general well-being of the family caregiver [7–9]. Depression combined with high burden, stress, and

burnout in the caregiver is in more than 80% of cases directly related to the premature ending of home care [10].

It is clear that these informal caregivers should be considered as a weak but indispensable link in the daily home care of demented patients. Although many studies recognize caregivers as hidden patients, in daily practice they are treated only as partners in care. Relatives of dementia patients are more actively involved in the care-giving process than is the case for other chronically ill patients, acting as care coordinators, information sources, and front-line communicators for the demented patient. Due to a lack of time, the complexity of the care situation, or social

General practitioners of dementia family caregivers should address in particular the needs and requests of these indispensable partners in home care.

- Both general practitioners and family caregivers report considerable obstacles in the shared care of a demented relative.
- Most general practitioners acknowledge their shortcomings in dementia home care but feel also reluctant to guide this time-consuming care process.
- Misunderstandings and obstacles between family caregivers and general practitioners can mainly be attributed to poor communication.

inhibition family caregivers are unlikely to put themselves forward for help. Consequently, a dementia home-care situation implies a dynamic and time-consuming three-sided relationship between the family, the demented patient, and the general practitioner [11,12]. Healthcare workers are trained specifically to focus on the care needs of the patient and tend not to consider the help-seeking family caregiver as a possible patient.

In answer to the concerns above, this literature review aims to identify the attitudes and perspectives of the family physician towards the caregivers of demented relatives and to describe the caregivers' satisfaction.

Material and methods

Search strategy

The literature search was performed using Medline, Embase, Cochrane Database of Systematic Reviews and Controlled Trials, ACP Journal Club, and Dare. Reference lists were screened for additional articles. Paper-based searching was performed in *Acta Neurologica Belgica*, *Archives of Public Health*, *Huisarts Nu*, *Huisarts en Wetenschap*, all Belgian and Dutch journals that are not indexed in Medline. No time limit or limit in publication type was employed in these searches with an actual time span from 1980 to 2007.

Finally, the databases were searched through for expert opinions, reviews, descriptive and consensus reports, and guidelines useful to interpret the findings.

Key words and mesh terms

Family physician, family medicine, general practice, general practitioner, and dementia as well as

the abbreviations were the search terms used. An additional, exploratory search on primary care, family caregiver, and home nurse failed to produce any new articles.

Selection of articles

Retrieved articles were screened for eligibility by title and abstract.

Inclusion criteria and outcome measures

Publications were considered eligible for inclusion on the basis of study population and context, study design, and outcome measures. The study population had to consist of community-dwelling demented patients, their family caregivers, and a general practitioner. Intervention studies were excluded if the general practitioner was only involved as research partner or was the subject of study and where the focus was solely on the demented patient. Studies of patients frequenting day-care centers or living in residential settings were also not included. Cross-sectional studies, longitudinal studies, and controlled trials were retained and guidelines, reviews, and expert opinions were collected as background information.

Primary outcome measures were described as the generic tasks and skills of the general practitioner to improve home care from the perspective of the family caregiver. In particular, the participating general practitioners were assessed for knowledge of and confidence in diagnosis and treatment, communication and coordination skills, and for dementia care obstacles in dialogue with the family caregiver. Caregivers were assessed on satisfaction concerning the care provided by their general practitioner.

Analysis

The collected data were systematically described and qualitatively assessed according to the Delphi criteria without statistical analysis (quality checklist according to Delphi criteria (Verhagen AP, et al. *J Clin Epidemiol* 1998;51:1235–41)). This checklist, developed by the Delphi Consensus Group, contains a list of generic criteria to assess the quality of randomized controlled trials. Although not fully appropriate for using in cross-sectional or follow-up studies, this checklist was considered to be of best value as a guideline for quality assessment.

Results

Retrieval and selection of studies

Figure 1 presents an algorithm of the retrieval, selection, and inclusion of articles. Papers listed more than once were excluded (caused mainly by overlapping between Medline and Embase and between the key words 'general practitioner and family practice'). Finally, a total of 44 articles were read thoroughly and assessed for compliance with the inclusion criteria leading to the selection of 16 for qualitative analysis. Twenty-eight articles did not meet all inclusion criteria or were reported in an inappropriate way.

Study characteristics

Only one randomized controlled trial and one intervention trial with a pre-post design were found. Thirteen cross-sectional studies and one longitudinal study were retrieved (Table I). In general the study populations were relatively small

with some exceptions (between 20 and 100 study subjects). Sample recruitment was mainly organized with the cooperation of memory clinics, day-care centers, or random mailings to general practitioners in a certain region. As a consequence response ratios were low, especially from general practitioners. The diagnosis of dementia was rarely formally tested. The family caregiver was defined as the primary informal caregiver, related to the demented patient but not necessarily living in the same house.

Outcome measures were basically formulated as caregiver's satisfaction concerning the care provided and as expectations regarding the general practitioner. Caregivers were also screened for feelings of grief and distress. General practitioners were assessed on their communication and coordination skills, confidence in and knowledge of the diagnosis and treatment of dementia, attitude towards family caregivers, and difficulties regarding dementia. Most studies reported on a mix of quantitative-qualitative data.

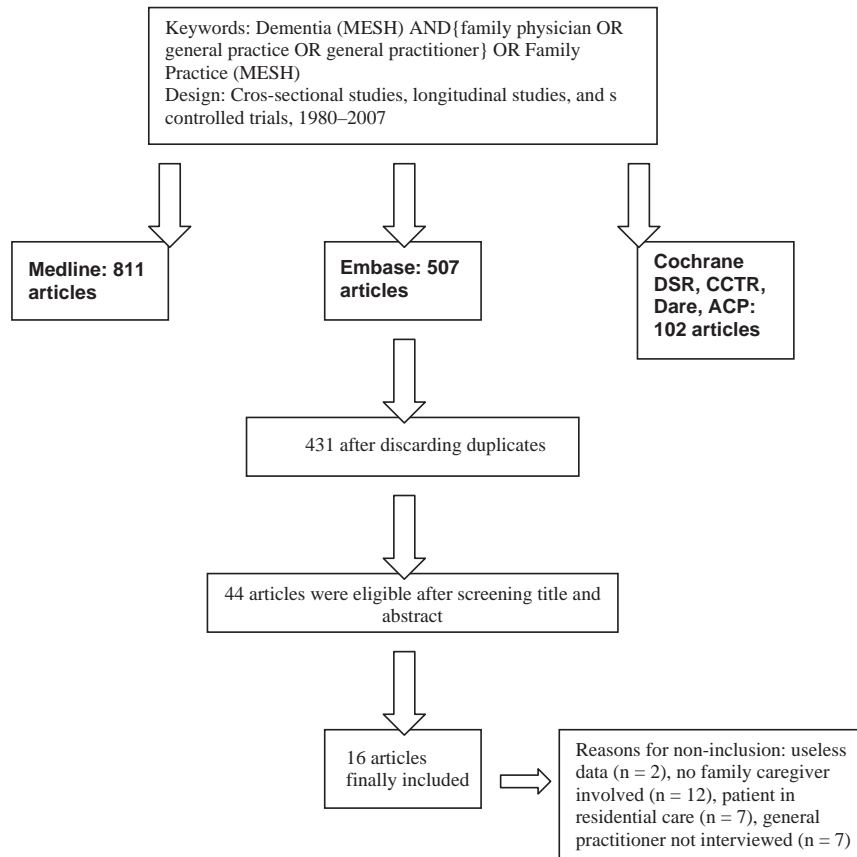


Figure 1. Flow chart of identification and selection of studies.

Table I. Overview of features of all included studies.

| Authors | Study design and participants | Method and intervention | Outcomes |
|--------------|---|---|---|
| Brodaty 1994 | Survey of 1473 GPs | Questionnaire on diagnosis and management | <ul style="list-style-type: none"> – GPs experienced difficulties in diagnosis and management – Diagnosis mainly based on passive forms of dementia – GPs reported a lack of standardized protocols for screening, referrals, treatment, and a lack of frontline cooperation and coordination |
| Bruce 2002 | Cross-section of 21 dementia family caregivers and their GP's | Qualitative study with semi-structured interviews GHQ-28 item on caregivers | <ul style="list-style-type: none"> – GP referrals in dementia care mostly 'urgent' or 'failing caregiver' – Caregiver: GP too busy and focused on medical matters, unaware of carer problems – GP: supported family but lack of time, caregivers resisted advice |
| Cheok 1997 | Cross-section of 20 GPs | Qualitative study with semi-structured interviews based on two cases for each participant | <ul style="list-style-type: none"> – Management: reviewing concomitant medication, underlying psychiatric disease, home safety but not ADL as major concern, search contact with informal support, few referrals to formal care, no long-term plan – Diagnosis: poor awareness of guidelines |
| Cherry 200 | Pre-post intervention study with 83 community-dwelling demented elderly patients and their GP | Diagnostic and management guideline, supported by social workers | <ul style="list-style-type: none"> – Caregiver and care provider satisfaction were higher after the intervention – Higher adherence of GPs to guidelines |
| Connell 2004 | Cross-section of 52 caregivers and their GP (39) | Qualitative study with semi-structured interviews for caregiver and focus groups for GP | <ul style="list-style-type: none"> – Caregivers: noticed resistance from GP in diagnosis, regretted delay in diagnosis, found communication of diagnosis insensitive, were in shock from diagnosis, felt left alone after diagnosis, suggested GP take more time and communicate in more compassionate way – GP: felt pressured by caregiver, regretted lack of time, felt disclosing diagnosis a challenge and an advantage towards caregivers, avoided 'dementia, Alzheimer, senility', disclosed diagnosis in presence of caregiver, reported family caregivers to respond well to diagnosis, provided information |
| Downs 2006 | Cluster randomized trial in 36 practices | Educational support: electronic tutorial, decision-based support and workshops | <ul style="list-style-type: none"> – Detection rates of dementia improved – Concordance with guidelines did not change |
| Glosser 1985 | Cross-section of 47 caregivers and 57 GPs | Interviews on role of GP in diagnosis, treatment and management | <ul style="list-style-type: none"> – Diagnosis: difficult for GP but rated helpful by caregiver – Treatment: frustrated regarding relief of symptoms; acknowledged psychosocial impact of dementia, least helpful according to the caregivers |

Table I (Continued)

| Authors | Study design and participants | Method and intervention | Outcomes |
|---------------|--|---|---|
| Lin 2005 | Cross-section of 111 dementia caregivers | 14-item questionnaire | <ul style="list-style-type: none"> – 97% of caregivers wanted disclosure of diagnosis by GP – 75% of caregivers wanted GP to disclose diagnosis to patient – 48% of caregivers received information about dementia through GP – Less than 5% of caregivers accepted term ‘dementia’, others preferred ‘memory loss’, ‘aging’ |
| McIntosh 1999 | Cross-section of 298 GPs and 487 nurses | Structured self-report questionnaire | <ul style="list-style-type: none"> – Over 50% of GPs: dealing with dementia patients and caregivers difficult – GPs more stressed than nurses by behavioral disturbances, social aspects of the disease – GPs found their role to be less useful than nurses – 70% of GPs routinely tested memory, 58% routinely tested depression in patients |
| Teel 2004 | Cross-section of 19 GPs, qualitative design | Telephone or in-person semi-structured interviews, data categories emerged during analysis, peer debriefing | <ul style="list-style-type: none"> – Time delay between first symptoms and diagnosis from months to a year – Denial in caregivers main diagnostic challenge – Diagnostic process time-consuming and complex – GPs reluctant to name dementia – Family involvement and support part of treatment – Careful listening most important skill in dementia care – Providing education to family highly important but difficult |
| Turner 2004 | Survey of GPs | Questionnaire on diagnosis and management skills of 127 GPs | <ul style="list-style-type: none"> – Good knowledge of diagnosis and management – Poor awareness of epidemiology and overestimation of case load – Poor knowledge of local support systems – One-third reported lack of confidence in diagnostic skills, two-thirds lack of confidence in management skills – Main difficulties: talking to caregiver about dementia, coordinating support and assessing problematic behavior |
| van Hout 2006 | Cross-section of 28 GPs, qualitative–quantitative design | Focus groups and questionnaires | <ul style="list-style-type: none"> – Tasks: guarantee quality of life of patient and caregiver, community services useful, care management not necessarily by GP, diagnosis, practice: take action in progressed stage – Obstacles: time, embarrassment, care management, diagnosis |
| Werner 2006 | Cross-section of 141 GPs, quantitative design | Structured telephone interviews based on two fictive cases, random assignment to one case | <ul style="list-style-type: none"> – Caregivers more involved by GP than patients, especially when patients’ behavior disturbed – 90% of GPs would try to agree with caregiver |

Table I (Continued)

| Authors | Study design and participants | Method and intervention | Outcomes |
|----------------|---|---|---|
| Wilkinson 2004 | Multinational survey, 741 dementia caregivers | Telephone interviews about caregiver's perception of diagnosis and treatment of dementia, care time, burden | <ul style="list-style-type: none"> – 4% of dementias first diagnosed by GP – Mean delay between symptoms and visit six months – Mean delay between symptoms and diagnosis 12 months – 75% of cases first presented to GP – 70% diagnoses made by second doctor (specialist) – 30% of caregivers dissatisfied with time delay for diagnosis – 50% of caregivers confident in diagnosis and treatment skills of GP, 75% confident in empathy of GP, 80% found GP easily accessible in this matter – At baseline caregivers wanted information about: possible treatment, future course of illness and cause of symptoms – Three years later caregivers wanted info about: possible treatment, future course and disease inheritance |
| Williams 1995 | Single cohort with follow-up after three years of 30 caregivers and their GPs | Interviews on information needs of caregivers | <ul style="list-style-type: none"> – 90% of GPs stated non-medical problems of caregivers as concern – 94% felt they met needs of caregivers – 46% handled caregiver problems themselves – 81% found management of caregivers' issues stressful – 75% stated payment system insufficient for handling caregivers' issues – 75% did not attend learning activities regarding caregivers – 80% found diagnosis difficult, 65% concerned about different agendas caregiver-patient |
| Yaffe 2002 | Cross-section of 142 GPs | Mailing of a 23-item questionnaire on demented-caregiver-GP relationship | |

Assessing the attitudes of the general practitioner in dialogue with the dementia family caregiver

Attitude and confidence of the general practitioner and caregivers' assessment towards diagnosis and treatment

Only one randomized controlled trial was found on the effect of intervention in improving the general practitioners' knowledge of dementia diagnosis and treatment [13]. Intervention consisted of three parts: an electronic tutorial, decision support, and workshops. The knowledge of the participating general practitioners was assessed by a theoretical questionnaire. At baseline, general knowledge of diagnosis, treatment, and referrals appeared to be good (70%) with poor scores on epidemiology (50%). Moreover, general practitioners confessed to have only limited confidence in their diagnosis skills and two-thirds lacked confidence in their management and coordination skills. Following intervention, rates of detected cases of dementia increased but adherence to guidelines of diagnosis and management did not improve.

One intervention trial with pre-post design was performed to determine how a managed care intervention impacted on the caregiver and how satisfied general practitioners were with dementia care [14]. Following intervention, general practitioners reported higher use of the MMSE (50% of cases) and an increased application of laboratory tests to support the dementia diagnosis (85% of cases). The study also revealed greater adherence by general practitioners to guidelines in dementia diagnosis and management.

In primary care surveys exploring the tasks and attitude of the general practitioner in dementia care management, general practitioners rated their theoretical knowledge as insufficient. Moreover, the general practitioners' guideline awareness appeared to be poor [15–19]. Most general practitioners rated the disclosure of the diagnosis to caregivers as a highly important issue, but were reluctant to use explicit terms such as 'Alzheimer' and 'dementia' [15,20,21]. Disclosing the diagnosis was seen rather as a time-consuming and burdensome process, largely because of the problem of denial on the part of caregivers [15,20,22,23]. In addition, general practitioners felt embarrassed about labeling their patient with cognitive impairment or dementia [24]. As a consequence, delay between the first symptoms of cognitive decline and the dementia diagnosis ran from a few months to more than a year [22]. Although caregivers expected their general practitioners to disclose the diagnosis, they noticed also resistance towards this topic [18,21,22,24]. Other caregivers were rather dissatisfied when the an-

nouncement of diagnosis took place in busy circumstances and they preferred a quieter moment without the usual disruptions [22,23].

The attitude of general practitioners towards the treatment of dementia was twofold. On the one hand, the limited use of cognitive-enhancing medication and the importance of reviewing concomitant diseases and therapies was acknowledged [17,18,25] while, on the other, the management of dementia in all its aspects was considered to be frustrating and unrewarding [18–20,23–26]. In particular, behavioral disturbances and psychosocial aspects were rated as highly difficult and not necessarily part of their job [15,24,26]. Caregivers reported their general practitioner to be unaware of the daily home-care problems and only half of the caregivers had confidence in the general practitioner's dementia-management skills [23,27].

Communication and coordination skills of the general practitioner

Following intervention, both caregivers and general practitioners reported greater satisfaction in their contact with each other [14]. In the primary care surveys that explored the tasks of the general practitioner in dementia-care management, most general practitioners reported feeling highly involved in dementia care. In contrast, caregivers found communication unsatisfactory and strongly regretted the time delay between first symptoms and diagnosis [22,23,27]. In this light it is relevant to mention that caregivers admitted that they did not appreciate the use of explicit diagnostic terms [21].

Regarding the stages following diagnosis, general practitioners referred caregivers to formal and informal support systems but did not propose a long-term care plan to the family caregivers [16,17,20]. Practitioners acknowledged the importance of education and information about dementia, but considered this an extremely difficult topic to communicate and coordinate [15,19,20]. Caregivers stated that they wanted to be informed on the natural course of the disease, the cause of the symptoms, and any possible treatment [28]. Nevertheless, caregivers complained that general practitioners focused exclusively on medical problems [23].

Obstacles experienced by the general practitioner and assessed by the caregiver in dementia home care

Owing to their lack of time, general practitioners estimated that their input in the organization of home-care was less useful than that of other frontline

health workers [22,26]. General practitioners reported a lack of understanding of, inadequate referrals to, and cooperation with frontline support systems [15,29]. They also believed that they involved the caregivers in planning home care and met most of their needs [22]. However, in reality most general practitioners appeared to be very unfamiliar with this area of dementia care [15,16,19]. Caregivers reported that general practitioners were least helpful and most ignorant regarding their own needs and worries [18,22].

The treatment of dementia was considered to be the major obstacle in the care-giving process. Regarding the patient, on the one hand, general practitioners acknowledged the limited use of cognitive-enhancing medication and the importance of reviewing concomitant diseases and therapies [17,18,25], but regarding the caregiver, on the other, they found the management of dementia in all its aspects to be frustrating and unrewarding [18–20,23,24,26]. General practitioners acknowledged the severe impact of the disease on the caregiver. Behavioral disturbances and all psychosocial aspects were rated as highly difficult and not necessarily part of their job [15,24,26].

Discussion

Although much has been written about the three-sided relationship between the general practitioner, the community-dwelling demented elderly patient, and the family caregiver, only a few studies have been conducted to investigate the role played by the general practitioner towards the family caregiver. On the basis of these few reports, it can be stated that the general practitioner is aware of his/her skills and limits in the medical and psychosocial aspects of dementia care and his/her role towards the family caregiver. Interventions to improve these skills show some impact on awareness and general knowledge, but only for a limited time. In surveys of primary dementia care the theoretical knowledge of the general practitioner was found to be good, but guideline awareness was rather poor. General practitioners acknowledged the importance of an adequate diagnostic process, but they felt uncomfortable disclosing the diagnosis to both the patient and the caregiver. They reported having more confidence in treatment matters than in diagnostic stages. Treatment of dementia with respect to the caregiver was found to be time-consuming and highly frustrating. Caregivers' reports on the attitude of their general practitioner in the diagnostic process were ambiguous. On one side they rated the general practitioner as indispensable, helpful, and comprehensible on this topic. On the other, they regretted the apparent

lack of time and empathy the general practitioner exerted.

General practitioners found themselves to be highly involved in dementia home care, but caregivers generally rated their involvement to be insufficient. Although caregivers seemed confident in the general practitioner's appraisal, they were generally dissatisfied with the qualities of support. The lack of appropriate communication skills of general practitioners was also not appreciated by the caregivers. Strikingly, caregivers were also rather reluctant to initiate communication on emotionally loaded topics, such as diagnosis or care management. A lack of time and reward was considered by the general practitioner to be the major obstacle in dementia care. General practitioners did not attach high value to their input in dementia care when compared with other primary healthcare workers. Both general practitioners and caregivers found the process of organizing home care for a demented patient to be troublesome. Moreover, family caregivers stated that the general practitioner tended to be unaware of their worries and feelings of grief and distress.

These results are in accordance with findings in other reviews and guidelines, but with some important new emphases [29–32]. The general practitioner is expected to guide the dementia process from the very beginning, to refer on time, to coordinate home care, to start and follow through treatment issues, to coach the caregiver, and to stay actively involved in this dynamic care process. This review now reveals a large discrepancy, on the one hand, between how general practitioners rated their own knowledge of dementia care and more objective assessments and, on the other, how general practitioners estimated their own involvement in dementia care and the lack of awareness reported by caregivers. Earlier reviews focused on the tasks and attitudes of general practitioners, rather than their skills, and failed fully to take the perspective of family caregivers into account.

Family caregivers and general practitioners both acknowledge the need to assess the general well-being of the caring relative. The general practitioner should attempt to produce a full inventory of care-giving stresses and estimate their impact on the well-being of the caregiver [33]. It is known that overloading the role of the caregiver can lead to early institutionalization and abuse of the elderly [33]. However, psychosocial items concerning patient and caregiver are considerably less popular during anamnesis [34]. Guidelines and a manageable care plan could help general practitioners tailor care management to the care needs of the caregiver and the demented patient [34]. In this regard, it is

interesting to note that general practitioners do not seem to be entirely convinced of their key role in the practical management of home care [24,26]. Also important in care planning is the issue of adequate referral to care-supporting systems. Caregivers too often feel bypassed when it comes to support of home care. In addition, studies reveal that interventions that are not previously discussed with the caregiver and which occur in an acute situation fail to achieve the expected result [10]. Most dementia care referrals occur at an acute stage, but are destined to fail because of feelings of guilt and doubt on the part of the caregiver [35].

Finally, assessment of the care situation and its impact on the general well-being of the caregiver can be approached in a structured way [30,36,37]. Although most of the trials reviewed did not make use of validated questionnaires, these instruments proved to have real value [31,34].

To our knowledge, this is the first review to explore both the general practitioners' point of view and the caregivers' appraisal of primary dementia home care. This resulted in the discovery of an important discrepancy between the appraisals of both groups. The weakness of the study is partially due to a lack of appropriate trials with high-quality designs on this topic. Besides, intervention studies aiming to improve the skills of the general practitioner with respect to the caregivers' outcome are rare. The main reason for the lack of reports covering the general practitioner's role in dementia care management might be the work overload suffered by family caregivers and general practitioners alike [22,23]. Above all, there are other subject-related features that limit the ease with which studies of this sort might be completed. First, with a mortality rate around 30%, a large number of patients might be expected to drop out during the course of the study [38]. Second, caregivers do not consider themselves as patients and will therefore be reluctant to participate in studies on this topic [39,40]. Third, the relatively low prevalence of demented patients in a general practice (15% above 65 years of age) will limit the recruitment of study subjects [41]. Another important constraining factor lies in the population studied. Studies are likely to be severely influenced and weakened by the fact that over 85% of patients are highly satisfied with their general practitioner [42].

Conclusion

Most general practitioners feel adequately skilled but report a moderate reluctance to guide community-dwelling demented elderly patients and their caregivers. Their key role as care provider and care

planner is consolidated by the family caregivers' confidence in their skills. Nevertheless, these caregivers report some important gaps in the communication skills of their general practitioner. Family caregivers expect to be informed about the diagnosis and possible treatment of the dementia, but are not open to the discussion of problems. From this point of view it is not surprising that general practitioners rate dementia home care as frustrating and very time-consuming. If communication can be more open between both parties, family caregivers will be less reluctant to report feelings of burden, depression, and stress. A systematic assessment of the caregivers' general well-being, performed by the general practitioner, is essential for the prompt adjustment of home care. Clear and efficient guidelines from early diagnosis to adequate referrals will certainly improve the ability of the general practitioner to support these time- and energy-consuming home-care situations. Consequently, intervention trials focusing on the skills of the general practitioners could be helpful in improving home-care outcomes regarding the family caregiver.

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