

## Integrated dementia care in The Netherlands: a multiple case study of case management programmes

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### Abstract

The number of dementia patients is growing, and they require a variety of services, making integrated care essential for the ability to continue living in the community. Many healthcare systems in developed countries are exploring new approaches for delivering health and social care. The purpose of this study was to describe and analyse a new approach in extensive case management programmes concerned with long-term dementia care in The Netherlands. The focus is on the characteristics, and success and failure factors of these programmes.

A multiple case study was conducted in eight regional dementia care provider networks in The Netherlands. Based on a literature study, a questionnaire was developed for the responsible managers and case managers of the eight case management programmes. During 16 semistructured face-to-face interviews with both respondent groups, a deeper insight into the dementia care programmes was provided. Project documentation for all the cases was studied. The eight programmes were developed independently to improve the quality and continuity of long-term dementia care. The programmes show overlap in terms of their vision, tasks of case managers, case management process and the participating partners in the local dementia care networks. Differences concern the targeted dementia patient groups as well as the background of the case managers and their position in the local dementia care provider network. Factors for success concern the expert knowledge of case managers, investment in a strong provider network and coherent conditions for effective inter-organizational cooperation to deliver integrated care. When explored, caregiver and patient satisfaction was high. Further research into the effects on client outcomes, service use and costs is recommended in order to further analyse the impact of this approach in long-term care. To facilitate implementation, with a focus on joint responsibilities of the involved care providers, policy recommendations are to develop incentives for collaborative financial contracts between insurers and providers.

**Keywords:** case management, integrated care, long-term dementia care

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### Background and purpose

In order to remain safely in the community, people suffering from long-term conditions such as dementia require a wide variety of services like home care, welfare and social services, as well as adequate housing and good medical

and nursing care (Bodenheimer *et al.* 2002a,b, Nies & Bergman 2004). Developing approaches to coordinating these services in a quality-driven and cost-efficient manner is a global concern. In order to respond to the needs of people with long-term conditions, many developed countries are also exploring new approaches such as integrated

care arrangements for delivering health and social care (Weiner *et al.* 2002, Ofman *et al.* 2004, Ouwens *et al.* 2005, Tsai *et al.* 2005).

### **Dutch policy context**

In The Netherlands, professionals in dementia care work in three sectors: (1) general care (care and somatic cure for acute and chronic diseases); (2) mental health care (psychiatric care, social and addiction care); and (3) long-term care of elderly people. The Dutch financial system is a complex social insurance-based system with multiple components and a clear split between acute health care and long-term and social care (Van Raak *et al.* 2003). Recent national policies emphasise a concern for the quality of life of elderly people, moving away from institution-based care and using home-care technology (Ministry of Health, Welfare and Sports 2007). The combination of growing needs for health and social care with budgetary pressure means that cost containment is essential; this occurs by reducing and delaying institutionalization. New legislation hands over the responsibility for purchasing home care and welfare to the local governments (Ministry of Health, Welfare and Sports 2006). For dementia care, this means that the total range of care and services has to be provided from different financial systems and policy sectors, each working within its own rules. There is much fragmentation in dementia care, yet policy-makers and professionals advocate integration and seamless care. During the onset and early stages of dementia, support is mostly provided by primary care practitioners, spouses, relatives and patient foundations. For medical diagnostics, general practitioners (GPs) can refer people to specialist memory clinics in a hospital or to mental health services. After diagnosis, local services determine the specific care packages such as case management, support groups, respite care, training or counselling. When living at home is no longer possible, elderly peoples' wards in nursing homes or sheltered housing are options (Dutch College of General Practitioners 2003, CBO; Dutch Institute for Healthcare Improvement 2005).

### **Room for improvement**

Although GP services, diagnostic clinics and home care are available for almost all patients in The Netherlands, the quality of dementia care is subject to multiple deficiencies and inter-regional differences. Areas for improvement include early detection of the disease, support after medical diagnosis and under-diagnosis of patient and caregiver depression. Lack of care coordination, timely referrals and information flows between health professionals and services are other areas for improvement (Health Council of The Netherlands 2002). As a part of the

National Dementia Programme (NDP 2008), family panels with over 600 participants formulated improvement areas in more than 50 healthcare regions. Families cited the need for systematic help in finding and arranging care, and reported a lack of continuity in long-term support. Systematic practical help and support after diagnosis are also missing, together with advocacy and education in coping with problematic behaviour. Caregivers living at home with a person with dementia experience an increasing burden over time (Dutch Alzheimer Association 2006). Adequate support for caregivers is crucial for sustaining people with dementia in the community. Where there is no caregiver or where the caregiver is depressed or stressed, the likelihood of nursing home admission rises sharply (Brodsky *et al.* 2003).

### **Case management programmes**

The increasing number of people with dementia, together with the problems and fragmentation of dementia care services, led to the development of case management programmes in various regions in The Netherlands. The initiatives are characterised by long-term support and guidance both for caregivers and people with dementia living in the community during all phases of the disease. Care and support are delivered by an appointed case manager, mostly employed by a nursing home or mental healthcare service (Ligthart 2006). Case management as an intervention has also been implemented in integrated care programmes for other patient groups. The Case Management Society of America describes case management as a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and the available resources to promote quality, cost-effective outcomes (CMSA 2008). The case manager or team takes responsibility for guiding the person through the complex process of care in the most efficient, effective and acceptable way. The case manager can also provide support with practical advice and social or emotional support. Sometimes, case finding, training of professionals and crisis intervention are also included. Case management models are often centred on the person with dementia (and caregiver) are integrated and provide outreach help (Rheume *et al.* 1994, Sledge *et al.* 1995).

It appears that case management is an intervention that works on two complementary levels. First, at an individual level, where the case manager provides advice or referral, and works in partnership with caregivers to refine the care plan and care process. Second, at the level of the care network, the case manager has a central position and collaborates with multiple healthcare providers, and provides continuity between professionals and organizations.

With the need to improve the quality of dementia care and the growing interest in case management initiatives in The Netherlands, a deeper insight into such intervention was considered necessary. Until now, no studies have been published that analyse the characteristics and forms of implementation of existing programmes. We, therefore, investigated the following research questions: (1) What are the characteristics of Dutch case management programmes in dementia care? and (2) What are the success and failure factors for the implementation of the programmes?

### Study design and methods

To answer the study questions, we conducted a multiple case study. A case study is defined as an empirical inquiry that investigates a contemporary phenomenon in its real-life context (Yin 2003). Case study methods were chosen because covering contextual conditions is essential when researching case management programmes. This study has a signalling function and does not claim to cover all (aspects of) programmes nor to identify causal relationships. To avoid confusion, we will use the word 'programme' when we discuss the research cases of regional care networks with case management.

Programmes were traced by means of consultations with and referrals by national experts in dementia care, publications and publicly available information. The study includes a representative number of case management approaches. Nine programmes were selected using the following criteria. First, case management had to have been implemented for at least 1 year, and programme documentation such as aims, planning and patient information had to be available. Second, programmes had to work with multiple case managers focusing particularly on dementia patients and their caregivers living in the community. Eight programmes agreed to participate. One programme did not take part because the programme manager was on a sabbatical leave.

The programme leaders were informed about the study by telephone and e-mail, and asked to provide programme documentation. All programmes provided project documentation; three programmes also provided evaluation reports and four programmes provided client information materials.

In order to obtain a broad perspective, two respondents from each programme, the responsible manager and a case manager, were asked to participate. All respondents agreed.

After a non-systematic literature study for international studies on comparable programmes in dementia care (search terms: dementia, Alzheimer, case management, care management, care coordination, integrated dementia care, caregiver support), we developed a

questionnaire with seven categories: programme history, motives and tasks, patient group and caseload, background and capacities of case managers, case management process, collaboration in the dementia provider network and implementation success and fail factors (Newcomer *et al.* 1999a,b, Chu *et al.* 2000, Eloniemi-Sulvaka *et al.* 2001, Challis *et al.* 2002, Aupperle *et al.* 2003, Banks 2004, Callahan *et al.* 2006). The above categories are comparable to those used in England (Challis *et al.* 2001, Weiner *et al.* 2002).

The semistructured interview guide was developed and reviewed by experts from the National Dementia Programme (NDP 2008). The interview questions were e-mailed to the respondents as a preparation for the interview. Over a 4-month period, 16 90-minute, semistructured, face-to-face interviews were conducted to discuss the items in the questionnaire. In one programme, two managers were involved in the manager interview; in another programme, there was one interview with the manager, who was also a former case manager. The interviews were tape recorded and transcribed ad verbatim. Patient flow charts as well as tables of the core aspects were constructed for each initiative. All materials were checked and confirmed by the respondents. Subsequently, in our analyses, the structured overviews of the different programmes were compared and contrasted with the previously named categories. The focus was on differences and overlap between the programmes, and less on differences between types of respondents.

### Main findings

The results of the seven categories, namely, programme history, motives and tasks, patient group and caseload, background and capacities, case management process, collaboration in the dementia network and success and failure factors are described as follows. The main characteristics of the programmes named A–H are summarised in Table 1.

#### Programme history

The case management programmes were set up between 2000 and 2005, and employed between three and 22 case managers. Multiple healthcare organizations, professionals and sometimes client organizations were involved in all programmes. The initiating healthcare organizations were mostly mental health care, nursing homes and home-care organizations formed part of a network or care chain to execute the programme. In one region, this collaboration had become transformed into an independent foundation, while in another region the programme was organised independently by the local government, in cooperation with the local healthcare

**Table 1** Characteristics of Dutch case management (cm) programmes

Region no. of case managers	cm since	Target group	cm tasks	Start and end points	Diagnostics included	Embedded in MDT	Providers	Involved parties in the care chain	Effects measured
Noord-Kennemerland (A) <i>n</i> = 22	2000	(Suspected) dementia, caregiver, mci	Extensive cm, training colleagues, aftercare	S: GP or specialist referral E: NH, death	+	+	Mental health, nursing homes	GPs, hospital, mental health, home care	+ Client satisfaction
Haarlem (B) <i>n</i> = 15	2001	Dementia, caregiver	Extensive cm, cg training, aftercare	S: any referral after diagnosis E: NH or RH, death	-	-	Mental health, nursing homes, home care	Dementia care network (all parties), patient associations	-
Tilburg (C) <i>n</i> = 3	2003	(Suspected) dementia, caregiver	Extensive cm, case finding, aftercare	S: any referral or own initiative E: NN, NH or RH, death	-	-	Mental health, Alzheimer's association, caregiver network	Independent from care network, local government	+ Client and professional satisfaction
Zoetermeer (D) <i>n</i> = 4	2003	Dementia, caregiver	Extensive cm, cg training, aftercare	S: mental health referral E: NH or RH, death	-	+	Nursing homes, home care	GPs, hospital, mental health	-
Groningen (E) <i>n</i> = 11	2004	(Suspected) dementia, caregiver	Extensive cm, aftercare	S: GP or specialist referral E: NH or RH, death	+	+	Mental health, nursing homes	GPs, hospital, home care	-
Eindhoven (F) <i>n</i> = 9	2005	(Suspected) dementia, caregiver, mci	Extensive cm, cg training, aftercare	S: GP referral E: death	-	-	Dementia care network, mental health, nursing home, home care	Dementia care network (all parties), patient associations	-
Delft Westland-Oostland (G) <i>n</i> = 3	2005	Dementia, caregiver	Extensive cm, case finding, cg training, aftercare	S: GP, specialist or home care referral E: NH or RH, death	-	-	Dementia care network, patient associations	Dementia care network (all parties)	-
Leiden en Oegstgeest (H) <i>n</i> = 11	2005	Dementia, caregiver	Extensive cm, cg training	S: GP or specialist referral E: NN, NH or RH, death	-	-	Mental health, nursing homes, home care	Dementia care network (all parties), patient associations	+ Client, GP and professional satisfaction

cg, caregiver; GP, general practitioner; mci, mild cognitive impairment; NH, nursing home; NN, no need; RH, residential home for the elderly.

providers. The reasons for starting the programmes in most regions were the increasing numbers of elderly mentally infirm clients in the caseload of social workers or (specialised) nurses and the growing need for more client-tailored services for this client group. This need was enforced by the recognition that specific knowledge about a broad range of aspects of dementia care was necessary for the provision of quality care. Client organizations emphasised that supportive and professional care to guide the client and her/his caregivers through the care process was missing. All the programmes stated that the start-up of the programmes was time-consuming and complex because of the many decisions and parties involved. Not only did arrangements about employing and financing case managers have to be made, but discussions about background and tasks, the case management process and the position of case managers in the dementia care network also took time.

### Motives and tasks

The need for easily accessible and client-centred care for both the dementia patient and their caregivers living in the community during the total care process was the most important factor in all programmes. All the programmes sought to ensure an independent role for the case manager in order to advocate clients' needs as effectively as possible. Establishing warm and confidence-based links with the client and their social system was cited unanimously as crucial for providing good quality care as a case manager. The tasks of case managers covered in all programmes consisted of care assessment, care planning, facilitation and implementation, evaluation and advocacy and family interventions (together defined as extensive case management). In most of the programmes, some kind of aftercare following nursing home admission or death of the patient, such as emotional support for the caregiver, was available but often limited in duration. Case managers also sometimes provided training for caregivers, for example, in coping and handling strategies (see Table 1).

### Patient group characteristics and caseload

In half the programmes, a confirmed diagnosis of dementia was a necessary inclusion criterion for case management in order to receive reimbursement of the costs of services or to regulate client numbers when starting up the programme. The other programmes included people with suspected dementia with a view to persuade them to enter the diagnostic process, or also included people with mild cognitive impairments. The programmes provided support to both the people affected and their (main) caregivers, living independently in the

community. The severity of the dementia or the availability of caregivers was never an inclusion or exclusion criterion. In the case of admission to a nursing home, the nursing home staff continued to provide the care and support. The case managers suggested that the most favourable model would be case management from the very first onset of dementia, even before the diagnosis had been confirmed. The reasons for this are the need for support and information in the early stages, and the relatively long period required to establish the diagnosis. The caseload of case managers ranged from 40 to 65 client dyads (client and caregiver) per full-time equivalent (FTE), with an average of 50. The case managers experienced their caseload as a maximum.

One programme was aiming at a caseload of 100 clients per FTE, but stated that it was not yet clear if this was sustainable. Increasing the caseload was felt to be a risk by shifting from proactive towards more reactive care and support.

### Background and capacities of case managers

The backgrounds of the case managers varied among and within programmes. In three programmes (B, D, G), the case managers were nurses, often specializing in elderly people's care or mental health. In the other programmes, the case managers were either specialist nurses or social workers. In four programmes (A, C, F, G), the case managers received specific training before starting their job.

As quoted (programme B): 'You really need specific knowledge about dementia and the characteristics of the disease. You have to analyze what goes wrong, give helpful advice and organize what needs to be done'. Skills required by the case managers included analytical qualities, the ability to work in a patient-centred rather than organization-oriented way, good communication skills, a good understanding of local services and provision, the ability to bond with patients and families, the ability to collaborate with a wide range of professionals, negotiating skills, perseverance and creativity. The respondents stated that case managers should preferably be more experienced nurses or social workers, because of the number of skills needed and the complexity of the work at both client and care network level.

### The case management process

The start of the case management process differed from one programme to another. In one programme (C), no diagnosis was needed, and anyone could refer. In this programme, the support provided also ended when there was no longer a need, but this occurred only occasionally. In most programmes, there were multiple

**Table 2** Success and failure factors of implementation

Success factors	Failure factors
1. Investment in a strong provider network or care chain, and good personal connections with professionals	1. Distrust of the programme by local providers and competition for delivering care
2. Expert knowledge of the case managers	2. Inadequate or no structural funding of the programme and programme coordination
3. Embedding in a multidisciplinary team and direct connection with medical staff	3. Little or no involvement of primary care specialists like general practitioners
4. Support and recognition of local providers for the programme	4. Doubt about the added value of case managers relating to existing care and support
5. The low threshold for accessing support and care for patients and caregivers	5. Not including patients without a confirmed diagnosis of dementia

ways of entering the case management process. Often, this was by referral from a GP (required in programme F) or specialist such as a neurologist, geriatrician or mental health specialist. The involvement of local GPs is cited as difficult, but important for proper referrals. When asked about the average number of contacts with clients, the case managers stressed that the frequency of contact largely depended on the client's situation. Contact frequencies vary from several times a day (in new, complex or near-crisis situations) to once every 3 months (in more stable or well-supported situations). All case managers provide home visits and consultation by telephone. In three programmes (A, D and E), case management is embedded in a multidisciplinary team (MDT). In programme A, this team consisted of case managers, social geriatricians, nursing home doctors, a psychiatrist, (neuro)psychologists, a dementia consultant for education and administrative staff. In programme E, the MDT consisted of case managers, social geriatricians, psychologists and transfer nurses. Both teams provide medical diagnostics, care assessment and long-term support by the case manager. In programme D, the case manager is part of an MDT which consisted of a nursing home doctor, a nursing home psychologist and psycho-geriatric nurses, but for medical diagnostics the team refers its patients to mental health services. The case manager has an important proactive role in the team. As quoted (programme D): 'The case manager has to be one step ahead all the time and inform and involve the team members. So when a situation escalates, everybody is already prepared'. The other case managers are not members of an MDT, but connect with an existing MDT of one of the partners or organise meetings as necessary.

### Collaboration in the dementia care provider network

The organizational structures and local collaboration varied from one programme to another. In most programmes, the case management initiative is embedded in the local dementia care network or care chain initiative,

which consists of all the local providers involved in dementia care. The aim of these networks is to improve the coherence and quality of dementia care in a certain local region, or to start new initiatives. Alzheimer's patient associations are also included in these networks. In one programme (A), the case management initiative developed into an independent foundation which also included medical diagnostics, temporary admissions and treatment facilities. The foundation works in collaboration with the local hospitals, home-care organization and GPs. In programme E, the case management team forms part of a collaborative agreement between the mental health services and local nursing homes. In some programmes (D and H), coordinating tasks are given to one of the parties or the participating parties as each employed a number of case managers who together formed a team. Local authorities were involved in only one programme (C), where it has a role in funding the case managers who are employed by a nursing home organization. The respondents all stressed the importance of adequate collaboration between the case managers and the local care providers in order to make the case management process really work. As quoted (programme A): 'A vivid and strong network of care providers is essential for delivering quality case management'.

### Success and failure factors

According to the respondents, a number of factors affected the likelihood that a programme would succeed or fail. The most frequently mentioned success or failure factors are summarised in Table 2. Others stated success factors were the growth in client numbers in programmes expressing the need for the support delivered and the effects of the programmes on clients. Respondents unanimously reported positive reactions by clients and professionals, the expected delays in nursing home admission, fewer crisis situations and reduced stress among caregivers. However, none of the programmes could report systematic effect measures on indicators like clinical outcomes

or service use (time to nursing home admission, use of home or community services, crisis admissions). Three programmes (A, C and H) evaluated their client (and caregiver) satisfaction, and two programmes (C and H) also evaluated the satisfaction of professionals involved (Stoop 2005, Lange & Pot 2006, Ravensbergen *et al.* 2006). Whereas the first results show high scores on all dimensions, especially client and caregiver satisfaction, firm conclusions cannot be drawn due to methodological limitations and differences between the evaluations. Three of the programmes planned to start scientific evaluations, mainly focusing on measuring client and professional satisfaction.

## Conclusion

Although the case management programmes in this study have developed separately and in different regions of the country, this study on case management for people with dementia shows that the motives, aims and main characteristics of case management are comparable. All the programmes offer services that focus on increasing the continuity and integration of primary, specialty, mental and long-term health care. The programmes are crossing these boundaries for people living in the community and are being client and caregiver focused.

The 'intensive case management model' as described by Challis *et al.* (2001) and Banks (2004) corresponds most closely to the programmes investigated here. The shared core tasks model covers 'usual care' in The Netherlands and appears insufficient as usual care often lacks continuity and long-term support. Three programmes also correspond with the joint agency model, in which case management is embedded in a MDT. However, in our study, the case managers' tasks do not rotate among team members, but are delegated to one responsible case manager, usually a specialist nurse or social worker. When comparing the case management programmes with care arrangements in other countries, like the UK and Canada, it shows that the diversity of programmes in those two countries is large. However, the case managers in this study confirm that case management suits complex groups such as people with dementia. Challis *et al.* (2006) suggest that the presence of case management programmes can be seen as an indicator of the fragmentation of healthcare systems.

## Practical implications

The enthusiasm and conviction of the respondents that case management adds value to the 'usual care' are a striking finding in this study. The presence of an MDT or collaboration with existing teams strengthens the case management initiatives. Case managers who do not

engage in regular consultation with physicians perceive this as a lack. It seems that linking case management to medical decision-making (by having doctors 'near at hand') is a powerful combination. Case managers favour a broad multitask model throughout the whole care continuum. This includes regular case management tasks (care assessment, planning, linking, evaluation, advocacy, support and family interventions), and also case finding, aftercare and the training of professionals and caregivers. While there is not yet scientific evidence to support the hypothesis that such a broad model provides better outcomes, some studies do point in this direction. Acton & Kang (2001) studied interventions to reduce the caregiver burden in dementia care and found the strongest evidence for multicomponent interventions. Brodaty *et al.* (2003) concluded in their meta-analysis of psychosocial interventions for caregivers of people with dementia that the only feature that emerged as significant was involvement of both the patient and the caregiver in a structured programme. Practical support for the caregiver, involvement of the family, structured individual counselling and flexible deployment of a consistently present professional to provide long-term support were all important. Providing not only practical care but also psychosocial support activities is stressed by the case managers in this study, and is also an important finding in the study of Sargent *et al.* (2007).

A crucial factor in the development and implementation of these programmes is the position of the case managers in the dementia care provider network. Key factors are well-defined tasks and arrangements among the providers involved, and a willingness to cooperate with others, including the redistribution of functions and tasks. Health professionals could emulate social workers, who often fulfil the role of linking caregivers to available support, while GPs do this less often (Brodaty *et al.* 2005). When caregivers of people with dementia are aware of available support, the increase of service use is likely (Roelands *et al.* 2008).

The amount of integration as described by Wulsin *et al.* (2006) is reflected in the different developments of the programmes, which often start with improved referral, to consultative care, to collaborative care or integrated team care like in programmes A and E. Only in programme A was the organizational structure reframed around integrated care and combined with new financial arrangements with health insurers. The uncertainty of funding for the other programmes is a risk factor for the future.

## Recommendations for policy

The programmes are heavily dependent upon inter-organizational commitment, which is essential for

effective integrated care. In Dutch healthcare policies, both integrated care and competition are stimulated. As a reaction to increased (financial) pressures, healthcare organizations are reorganizing themselves and merging with others to develop new organizational structures (Fabbri 2007). These circumstances are critical issues for the further development and sustainability of the case management programmes. A study which compared the amount of integrated structures in relation to the quality of care revealed that integrated health and social care (in Ireland) versus the more fragmented situation (in the UK) did contribute to more multidisciplinary working and care management arrangements (Challis *et al.* 2006). Integrated care for elderly people with dementia seems to be desirable in several developed countries with an ageing population. However, policy recommendations are needed to guide these processes and to make care accessible throughout the community. The programmes described in this study could serve as a starting point to form a basic model for implementation of case management programmes on a broader scale. On a policy level, incentives for developing a sound knowledge base and exchanging experiences about case management programmes should be stimulated and facilitated. In The Netherlands, the National Dementia Programme and the local Alzheimer federations offer national infrastructures which could be further developed into a nationwide knowledge network which initiates, stimulates and disseminates knowledge about effective integrated dementia care. International learning in exchange programmes, like the National Dementia Strategy in the UK, is recommended (NDS 2008). Another policy recommendation is to stimulate the development of collaborative financial contracts between care providers and insurers. The very recent (2008) Dutch dementia programme which facilitates 10 dementia networks is a step in the right direction, but the urgency to improve dementia care asks for more experiments and incentives for both insurers and providers to contract integrated care.

### Evidence for effects

The limited data on the satisfaction of clients and professionals show high scores and underline the experiences of the case managers. However, there is a need for more evidence on the effects of the programmes. The published evidence regarding the effectiveness of case management interventions is equivocal. Two studies of dementia care (Newcomer *et al.* 1999a,b) found no effects over time with respect to institutionalization for two types of case management varying in terms of caseload and available resources. However, there were slight improvements in reduction of the caregiver burden and depression after 6 months. The case management was limited

to organizing good-quality, cost-effective care, without emotional and social support for clients and their caregivers. A study by Gravelle *et al.* (2007) about case management for frail elderly people found no effects on hospital admissions or mortality. Eloniemi-Sulvaka *et al.* (2001) describe a 2-year intervention programme in Finland by a dementia family care coordinator (a trained nurse). In this RCT, the rate of institutionalization was initially significantly lower in the intervention group, but the benefit decreased over time. Another study of case management for dementia patients (Challis *et al.* 2002), also focusing on emotional and social support, found effects on delayed nursing home admission, but not on the objective caregiver burden. In Canada (Chu *et al.* 2000), clinical intensive case management for early-stage Alzheimer's patients and their caregivers was also found to delay institutionalization after 18 months, without extra use of services. Next to this, caregivers felt less burdened at 6 months, but not in later measurements. Next to a preventive and proactive emphasis, the focus was on education, supportive counselling and skill training.

### Future research

In our opinion, future research on the effects of case management in dementia care should focus on two levels: the individual level of clients and caregivers, and the organizational level of the care network. At client level, measuring the effects on health outcomes such as caregiver burden, problematic behaviours and patients' and caregivers' well-being and depression is necessary. Also, the effects on care consumption are interesting to judge the cost-effectiveness of case management in the short and long term. At the level of the care network, the effects on service use such as time to nursing home admission, referrals or crisis interventions are suggested. The degree of integration, embedding in an MDT and breadth of the intervention package related to outcomes are subjects for further research. Consequently, in order to estimate the total effects, the financial consequences of case management programmes and changed service use patterns should also be researched.

### Limitations of the study

Our research contains several limitations. The number of programmes included in this explorative study was limited. The selection criterion that a programme had to have been in existence for 1 year may have excluded less successful, already failed programmes. Furthermore, apart from the manager, we interviewed one case manager per case as a representative of the case manager group. However, the cooperation of all the respondents

and the large amount of data from project documentation and the interviews provided a good insight into the characteristics of the programmes and the perceived success and failure factors. Despite these caveats, this multiple case study does support the conclusion that case management in dementia care, as being developed in The Netherlands, is a young but promising approach that should be further investigated. The increasing numbers of people with dementia living in the community and the deficiencies in the current healthcare system underline the need for the further improvement of integrated and coherent dementia care.

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### References

- Acton G.J. & Kang J. (2001) Interventions to reduce the burden of care giving for an adult with dementia: a meta-analysis. *Research in Nursing & Health* **24**, 349–360.
- Aupperle P.M., MacPhee E.R., Coyne A.C., Blume J. & Sanchez B. (2003) Health service utilization by Alzheimer's disease patients: a 2-year follow-up of primary versus subspecialty care. *Journal of Geriatric Psychiatry and Neurology* **16**, 15–17.
- Banks P. (2004) Case management. In: H. Nies and P.C. Bergman (Eds) *Integrating Services for Older People – A Resource Book for Managers*, pp. 101–112. EHMA, Dublin.
- Bodenheimer T., Wagner E.H. & Grumbach K. (2002a) Improving primary care for patients with chronic illness. *Journal of the American Medical Association* **288**, 1775–1779.
- Bodenheimer T., Wagner E.H. & Grumbach K. (2002b) Improving primary care for patients with chronic illness: the chronic care model, part 2. *Journal of the American Medical Association* **288**, 1909–1914.
- Brodady H., Green A. & Koschera A. (2003) Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society* **51**, 657–664.
- Brodady H., Thomson C. & Fine M. (2005) Why caregivers of people with dementia and memory loss don't use services. *International Journal of Geriatric Psychiatry* **20**, 537–546.
- Callahan C.M., Boustani M.A., Unverzagt F.W., Austrom M.G., Damush T.M. & Perkins A.J. (2006) Effectiveness of collaborative care for older adults with Alzheimer disease in primary care. *Journal of the American Medical Association* **295**, 2148–2157.
- Case Management Society of America (CMSA) (2008) Case Management Society of America, Little Rock, AR. URL <http://www.cmsa.org>
- CBO; Dutch Institute for Healthcare Improvement (2005) *Guideline Diagnostics and Medication Treatment of Dementia*. CBO, Utrecht, the Netherlands.
- Challis D., Weiner K., Darton R., Hughes J. & Stewart K. (2001) Emerging patterns of care management: arrangements for older people in England. *Social Policy & Administration* **35**, 672–687.
- Challis D., Von Abendorff R., Brown P., Chesterman J. & Hughes J. (2002) Care management, dementia care and specialist mental health services: an evaluation. *International Journal of Geriatric Psychiatry* **17**, 315–325.
- Challis D., Stewart K., Donnelly M., Weiner K. & Hughes J. (2006) Care management for older people: does integration make a difference? *Journal of Interprofessional Care* **20**, 335–348.
- Chu P., Edwards J., Levin R. & Thomson J. (2000) The use of clinical case management for early stage Alzheimer's patients and their families. *American Journal of Alzheimer's Disease & Other Dementias* **15**, 284–290.
- Dutch Alzheimer Association (2006) *Report of Family Panels in the National Dementia Programme*. Dutch Alzheimer Association, Bunnik, the Netherlands.
- Dutch College of General Practitioners (2003) *Practice Guideline Dementia*. NHG, Utrecht, the Netherlands.
- Eloniemi-Sulvaka U., Notkola I.L., Hentinen M., Kivela S.L., Sivenius J. & Sulvaka R. (2001) Effects of supporting community living demented patients and their caregivers: a randomized trial. *Journal of the American Geriatrics Society* **49**, 1282–1287.
- Fabbricott I.N. (2007) *Taking Care of Integrated Care. Integration and Fragmentation in the Development of Integrated Care Arrangements*. Optima Grafische Communicatie, Rotterdam, the Netherlands.
- Gravelle H., Dusheiko M., Sheaff R., et al. (2007) Impact of case management (Evercare) on frail elderly patients: controlled before and after analysis of quantitative outcome data. *British Medical Journal* **334**, 31–34.
- Health Council of The Netherlands (2002) *Dementia*. Health Council of The Netherlands, The Hague. Publication no. 2002/04E.
- Lange J. & Pot A. (2006) *First Results of Client Satisfaction*. The Netherlands Institute for Mental Health Sciences, Utrecht, Trimbos.
- Ligthart S.A. (2006) *Case Management for Dementia*. CBO Dutch Institute for Healthcare Improvement, Utrecht, the Netherlands.
- Ministry of Health, Welfare and Sports (2006) *New Rules According to the Law for Social Services*. Sdu Uitgevers, The Hague. Publication no. 2006/94714.
- Ministry of Health, Welfare and Sports (2007) *Care for the Elderly; Care for the Quality of Life*. Sdu Uitgevers, The Hague. Publication no. 2007/2771018.
- National Dementia Programme of The Netherlands (NDP) (2008) URL <http://www.dementieprogramma.nl>
- National Dementia Strategy of the United Kingdom (NDS) (2008) URL <http://www.dh.gov.uk>
- Newcomer R.J., Yordi C., DuNah R., Fox P. & Wilkinson A. (1999a) Effects of the medicare Alzheimer's disease demonstration on caregiver burden and depression. *Health Services Research* **34**, 669–689.
- Newcomer R.J., Spitalny M., Fox P. & Yordi C. (1999b) Effects of the medicare Alzheimer's disease demonstration on the use of community-based services. *Health Services Research* **34**, 645–667.
- Nies H. & Bergman P.C. (2004) *Integrating Services for Older People – A Resource Book for Managers*. EHMA, Dublin.
- Ofman J.J., Badamgarav E., Henning J.M., et al. (2004) Does disease management improve clinical and economic outcomes in patients with chronic diseases? A systematic review. *American Journal of Medicine* **117**, 182–192.

- Ouwens M., Wollersheim H., Hermens R., Hulscher M. & Grol R. (2005) Integrated care programmes for chronically ill patients: a review of systematic reviews. *International Journal for Quality in Health Care* **17**, 141–146.
- Ravensbergen C., Slooten E. & Wensem I. (2006) *Evaluation of Case Management for Dementia*. Steering Committee on Case Management, Leiden, the Netherlands.
- Rheume A., Frisch S., Smith A. & Kennedy C. (1994) Case management and nursing practice. *Journal of Nursing Administration* **24**, 30–36.
- Roelands M., Van Oost P. & Depoorter A. (2008) Service use in family caregivers of persons with dementia in Belgium: psychological and social factors. *Health and Social Care in the Community* **16**, 42–53.
- Sargent P., Pickard S., Sheaff R. & Boaden R. (2007) Patient and carer perceptions of case management for long-term conditions. *Health and Social Care in the Community* **15**, 511–519.
- Sledge W.H., Astrachan B., Thompson K., Rakfeldt J. & Leaf P. (1995) Case management in psychiatry: an analysis of tasks. *American Journal of Psychiatry* **152**, 1259–1265.
- Stoop H. (2005) *Evaluation of the Dementia Consultant Tilburg*. Brabants Ondersteunings Instituut Zorg BOZ, Tilburg, the Netherlands.
- Tsai A.C., Morton S.C., Mangione C.M. & Keeler E.B. (2005) A meta-analysis of interventions to improve care for chronic illnesses. *American Journal of Managed Care* **11**, 478–488.
- Van Raak A., Mur-Veeman I., Hardy B., Steenbergen M. & Paulus A. (2003) *Integrated Care in Europe. Description and Comparison of Integrated Care in Six EU Countries*. Elsevier Gezondheidszorg, Maarssen, the Netherlands.
- Weiner K., Stewart K., Hughes J., Challis D. & Darton R. (2002) Care management arrangements for older people in England: key areas of variation in a national study. *Ageing & Society* **22**, 419–439.
- Wulsin L.R., Soller W. & Pincus H.A. (2006) Models of integrated care. *Medical Clinics of North America* **90**, 647–677.
- Yin R.K. (2003) *Case Study Research. Design and Methods*. Sage, Thousand Oaks, CA.