8 & 9th March 2010

Case Management Workshop
Case Management, an international state-of-play

In the fight against Alzheimer’s disease and related disorders, the ultimate goal is obviously to find a cure of the diseases and to enable early diagnosis for early, targeted treatments. However, the time necessary to reach this goal is not predictable. In the meantime, it is essential to implement solutions that can alleviate, even partially, the plight of families.

Among these solutions, case management has been experimented and implemented in various countries, but not really in the France. It encompasses very diverse procedures and practices among which we need to adapt the best choice to our French health care system and cultural habits. Thus, the French National Foundation on Alzheimer’s disease has set up a state of the art of international experiences.

Created in June 2008 by the French Ministry of Research to implement the research measures of the National Plan, this non-profitable private foundation, ensure an efficient and highly reactive programming of research in the field of Alzheimer’s disease and related disorders.

Among the missions of the Foundation, the development of human and social sciences is a major scientific challenge. This symposium on case management is part of this challenge. This workshop represents the first step of a brainstorming that will lead to some recommendations and then to a larger dissemination. Major aspects will be analysed and discussed with the most outstanding international specialists of the field: the organizational and economical context, the professional practices and the specific clinical tools.

I am sure that useful information and practical guidelines will emerge from this workshop and warmly thanks our experts and all the participants who accepted, in very busy schedules, to participate for this two intense day session.

I wish you a fruitful meeting!

Philippe AMOUYEL
CEO of the Fondation Plan Alzheimer
Case or care management is already a well-established practice and, to a certain extent, a new profession in anglo-saxon countries, conversely to France. In our country, some practices of the public Long term care policy (Allocation personnalisée d’autonomie, personal allowance for autonomy) the local level could be considered, to a certain extent, as premonitions of “case management” (accompagnement individualisé). Indeed, the delivery of the allowance supposes a procedure of need assessment by medical practitioners and social workers associated to the definition of a care package. However, this type of procedure looks like particularly problematic for a dependency linked to psychic or cognitive disorders, dementia, and Alzheimer’s disease. Nevertheless, these practices could hardly be considered as case management and the development of such procedures is at stake. This is one of the reasons we expect to learn a lot about international experiences personified by outstanding experts from UK, Canada, US, Japan and Italy who kindly accepted to actively participate in this workshop. We already learned a lot from the well-known Kent and Gateshead’s experiences. Indeed, United Kingdom has implemented these practices in the early 90s, with the New Community Care reform after the publication of the White Paper “Caring for people” (1989). This White paper set out different objectives, one of which was “to make proper assessment of need and good case management, the corner stone of high quality care”. This policy momentum was developed under the global argument of free choice. Last but not least, one of the main objectives, more or less explicit, was also to hold public spending and if possible to reduce it, in particular by avoiding institutionalization of frail elderly people. From the experimentation and evaluation of case management at the local level emerged some main issues that could help significantly the French policy framing. These experimentations highlighted different issues: universal needs-based assessment to every potential user versus intensive care management targeted towards more dependent users; the split between provider and purchaser, to avoid the budgetary slides; the definition of a new profession associating both a heavy administrative component and a counselling dimension. Firstly, the concept of “need” is indeed very controversial and its evaluation is difficult to isolate from the availability of services. One could consider that need assessment corresponds frequently to what authorities are able to offer at a local level. Secondly, universal access to need assessment opens the door to potentially high public spending, while a more targeted or intensive care management with clients on the brink of institutional care is a guarantee to reduce costs. Thirdly, the profile of care managers and their practices depends on their previous occupation: social workers, occupational therapists, health care nurses, etc. Here are some basic lessons from the UK experience and we could also expand on the even longer US experience.

We proposed to the well-known international specialists of these practices in their respective countries who accepted...
to participate in this exercise, to develop a rapid synthesis of their experience on three main issues:

Firstly, the organizational and economical context: to better understand the way these practices developed in the respective countries, their policy framing and their main objectives (explicit and implicit), the funding models underneath and the reason why most of them remained at an experimental stage (either at territorial or duration levels). Other questions are pending: what could be the conditions for a larger implementation? What kind of economic model would be suitable for these assessment practices? What should be the success or failure criteria at an organizational level? How to assess the implementation and impact of these practices? What could be considered as an optimal size of territories for such practices in terms of efficiency?

Secondly, professional practices: this issue relates to the practical tasks of the case managers: number of people to be supported for a maximum efficiency, relationships with the informal network of the persons and with the professionals involved in the care arrangements, expected competencies and abilities, ethical issues, best training and curriculum, but also the difficulties (reluctance of the other professionals, depending on the profile and role of the care manager), and the level of representations (perception of the care manager by the users or customers). Do specificities to Alzheimer’s disease exist with regards to the case management process?

Thirdly, clinical tools of the case management: what are the different methods to select the cases and to define the target groups. What about the opinions of the different actors involved in the process of case management (users, family network, other professional, etc), what about these methods and tools? What are the strength and weakness of the specific procedures of case management, particularly in the cases of Alzheimer’s disease and related disorders? What about the possible sharing of information.

All along these three axes, we voluntarily decided to devote large period of time to discussions, questions and debates we hope to be exciting. Finally, we wish all the participants an excellent seminar and once more, warmly, thank all our international experts who accepted to deliver their experience and expertise that will help us to more firmly build up our French policy.

Marie-Aline Bloch
Scientific Director
CNSA

Claude Martin
Research Director
CNRS
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# CLINICAL TOOLS OF THE CASE MANAGEMENT

Chair: F. Pasquier, D. Somme

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# PERSPECTIVES OF THE CASE MANAGEMENT IN FRANCE

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## Sunday 7th, March 2010

7.30pm  Welcome Dinner on site, Participants & Speakers

## Monday 8th, March 2010

10.00am  Welcome Coffee and Opening Remarks:
Philippe AMOUYEL
Claude MARTIN

10.15am  **ORGANIZATIONAL AND ECONOMICAL CONTEXT**
Chair: Marie-Eve JOEL
Secretary of meeting: Marie-Aline BLOCH

- **David CHALLIS, UK**
- **Denis KODNER, USA**

11.30am  Coffee Break (30 mn)

- **Shinya MATSUDA, Japan**

1.00pm  Lunch on site

2.00pm  Round Table and general discussion

3.30pm  **PROFESSIONAL PRACTICES**
Chair: Jean-François DARTIGUES
Secretary of meeting: Matthieu DE STAMPA

- **Barbara G VICKREY, USA**
- **Christopher CALLAHAN, USA**

5.00pm  Coffee Break (30 mn)

- **Yves COUTURIER, Canada**

6.30pm  Round Table and general discussion

7.30pm  Dinner on site, Participants & Speakers
Tuesday 9th, March 2010

8.30am  CLINICAL TOOLS OF THE CASE MANAGEMENT
         Chair: Dominique SOMME
         Secretary of meeting: Florence PASQUIER
         • Réjean HEBERT, Canada
         • Roberto BERNABEI, Italy
         • Daphne NAHMIASH, Canada

11.00am  Coffee Break (30 mn)
11.30am  Round Table and general discussion
12.30am  Lunch on site

1.30pm   PERSPECTIVES OF THE CASE MANAGEMENT IN FRANCE:
         • MAIA experimenting: Olivier DUPONT
         • Synthesis & General discussion: Marie-Aline BLOCH, Matthieu
           DE STAMPA, Florence PASQUIER

4.30pm   Closing remarks: Professor Joël MENARD
Philippe Amouyel is Professor of Epidemiology and Public Health at the University Hospital of Lille in the North of France. He is in charge of a large academic research unit at Inserm (U744), working on public health and molecular epidemiology of ageing diseases. A part of his research activity is devoted to cardiovascular diseases, understanding the multiple determinants of coronary artery disease, stroke and aneurysms. The other part is focused on the study of determinants, mainly genetic, of neurodegenerative diseases associated with cognitive decline and of Alzheimer’s disease in particular. He develops large epidemiological studies in population to attempt to decode the individual susceptibility to ageing diseases, using molecular techniques (genome wide association studies, high throughput genomics, transcriptomics, proteomics and bioinformatics...). He participated in the preparation of the National Report on Alzheimer’s disease and related disorders headed by Prof. Joël Ménard. After the publication of the National Plan in February 2008, he was nominated at the head of the Fondation Plan Alzheimer to implement the research part of the National Plan. At the European level, he is leading the pilot Joint Programming Initiative on combating neurodegenerative diseases in particular Alzheimer’s disease. This initiative brings together 24 countries and aims at developing new ways of efficient collaboration in Europe.

Claude Martin, senior research fellow at the CNRS, director, Research centre on long term care, vulnerability and alzheimer disease at EHESP school of public health PhD in Sociology (university Paris 8), Habilité à diriger des recherches (université de Paris 5), Director of Research CNRS, Chair on ‘Social care’ at the EHESP School of Public Health; Researcher at the Centre de recherches sur l’action politique en Europe (CRAPE) – UMR 6051 CNRS, University of Rennes 1. He also teaches social policies in the following universities: Science Po Rennes, Conservatoire national des arts métiers, University of Rennes 2, Paris-Descartes

Member of the Scientific council of the EHESP (since october 2007); Member of the executive committee of the Fondation Plan Alzheimer (2008-2012); Member of the Scientific council of Institut national d’études démographiques (2005-2009); Member of the scientific council of the Groupement d’intérêt scientifique « Longévité et vieillissement » (CNRS-INSERM-INED- Fondation France Alzheimer) (2004-2007);

Vice-Président of the French Sociological Association, member of the executive committee (since 2006); Expert at the European Observatory on the social situation, demography and the family, European Commission (1998-2005); Associate Professor, department of sociology, Montreal University (1994- 1997); Invited Professor at the Institut national de la recherche scientifique « Culture et société », Montréal (november 1997 - may 2000).

Co-director of the international journal « Lien social et politiques » (Montréal, Paris); Member of the editorial committee of the following journals: Social Policy and administration (Blackwell UK), Sociologie (PUF, France); Politiques sociales et familiales (CNAF, France); collection « Res Publica », Presses universitaires de Rennes and director of a collection at the Presses de l’EHESP.

Claude Martin assumed the direction of an important amount of research contracts (47 since the beginning of his career) and in different programs: European commission PCRD, French research agency (ANR), Direction of research of the ministry of Health and Social Affairs, Caisse nationale des allocations familiales, etc. He published 99 papers in academic journals and 104 chapters in academic collective books. He also published 7 books and is the editor of 9 collective books. About a third of his publications are in English, but he also published in German, Portuguese, Italian and Spanish.
**ORGANIZATIONAL AND ECONOMICAL CONTEXT**

Chair:

**Prof. Marie-Eve JOEL** has a MSc in mathematics and a PhD in economics. She is Professor at Université Paris-Dauphine and director of the LEGOS (Laboratoire d’Economie et Gestion des Organisations de Santé) since 1998. Professor Joël is a specialist in quantitative economic analysis in the social field and in the implications for public policy of ageing questions. She has undertaken research and prepared reports on a number of issues in gerontology, social protection and dependence of the elderly in Europe, the economics of chronic pathology and health and long-term health care.

**Marie-Aline BLOCH** is an engineer of Ecole Polytechnique, PhD in biology et scientific Vice President of the french National funding organisation of Solidarity for Autonomy* (Caisse nationale de solidarité pour l’autonomie (CNSA). Beforehand, she was the R&D Secretary-General of Aventis Pasteur where she was in charge of the reorganisation of the R&D departments (upstream research, preindustrial development, clinical development and regulatory affairs), of the management of the R&D projects portfolio and the identification of new research targets. Beginning of 2000, she became vice President of the transversal research programs of the Pasteur Institute in Paris and developed many interdisciplinary national and international projects for public health. Since the beginning of 2006 at the CNSA, she is in charge of the management of the scientific Council of CNSA and of the implementation of a new policy for the development of research for autonomy and on disabilities in France. This includes medical, sociological, economical, demographic and technical issues and particularly the development of new technologies for the autonomy of disabled and elderly people. With this regards she has been supervising together with the National Research Agency (ANR) a prospective report on technologies for health and autonomy. She is member of the executive committee of the Fondation Plan Alzheimer.

*CNSA is the French public institution which has as a mission to finance care expenses for the autonomy of elderly and disabled people (role as a funding organization, annual budget 18 billions euros) and to improve the whole care system for autonomy loss of the elderly and disabled people (role as an agency).
ORGANIZATIONAL AND ECONOMICAL CONTEXT

Speakers:

- David CHALLIS
- Denis L. KODNER
- Shinya MATSUDA
David CHALLIS is Professor of Community Care Research and Director of the PSSRU at the University of Manchester. PSSRU is the largest centre in the UK focussing on social care. He has undertaken the development and evaluation of a series of studies of community based care for older people which provided alternatives to hospital and nursing home care and influenced. Currently he is responsible for national studies of care coordination in older people’s and long term conditions services and evaluation of assessment procedures in England. Other work includes performance measurement in older people’s services, hospital discharge, the evaluation of innovative approaches to flexible support such as personal budgets and old age mental health services. He is the author of 21 books and over 150 papers.

He has been an adviser on services for older people to the Commonwealth Government of Australia, Canadian Province of Ontario, Government of Japan, Government of Hong Kong, the US State Government of Wisconsin and the Department of Health in England and National Assembly for Wales.
This paper is designed to address the issue of case management in dementia care, and in particular its organisational and economic context. There are four sections to this. In the first, by way of background, the origins of case management, its definition and position in dementia care are considered. In the second, the evidence base for the impact of case management in social and healthcare settings in the UK is summarised. In the third section some factors associated with positive outcomes or effectiveness in case management are identified. Finally, in conclusion, some key factors to be addressed in case management development are summarised and some possible research questions/development issues for case management in dementia care are identified.

1. Background

The origins of case management

There are major developments in long term care occurring in many countries and some broadly similar trends can be discerned. In their study of emerging patterns of change in services for elderly people in the Netherlands, Sweden and The United Kingdom, Kraan et al (1991) noted three broad trends:

- a move away from institution-based care
- the enhancement of home-based care
- the development of mechanisms of coordination and case management

In the care of older people in many other countries such as the USA, Canada and Australia a similar trend can also be observed (Challis, 1992a,b). In mental health services, the reduction of institutional provision and focus upon community based services is clear (Huxley et al., 1990). Long-term care policy for other client groups has also taken not dissimilar forms, with the desire to develop community services being stressed (DHSS, 1983; Cm849, 1989). Underlying this is a major debate about the extent to which community services complement or substitute for institutional care.

Concern for coordination has been longstanding and in the UK took the form principally of attempts to improve inter-agency coordination, principally health and social care, through
such initiatives as joint care planning and joint financing. The focus upon coordination at the client level came considerably later being less evident in a setting where most services were provided by two main public sector agencies, health and social services. In the USA for people with learning disabilities discharge from hospital and developing continuity of care have been key themes, with case management made mandatory to improve coordination of care after discharge (Intagliata, 1982). The rationale for this is cited by Miller (1983) who quotes the conclusion of the US Presidential Commission on Mental Health for case management:

"Strategies focused solely on organisations are not enough. A human link is required. A case manager can provide this link and assist in assuring continuity of care and a coordinated program of services" (Miller, 1983, p5-6).

In general, therefore, the origins of case management lie in the `need to coordinate delivery of long-term care services to individual clients' (Austin, 1983, p16). Moxley (1989) cites six factors underlying the development of case management: de-institutionalisation, the decentralised nature of community services, growing numbers of clients with multiple needs living at home, fragmentation of care services, a growing awareness of the importance of social supports and carers, and the need for cost containment. Case Management and Coordination are thus central to the achievement of the goals of Community based care. The UK White Paper ‘Caring for People’ (Cm849, 1989) described Assessment and Case Management as the cornerstones of community care. In many jurisdictions the terms case management and care management are used interchangeably. Here the term ‘case management’ has been employed. The overall goal of case managers is to facilitate collaborative and cost-efficient interactions among service providers that effectively integrate medical, psychological, and social services in order to provide timely, appropriate, and beneficial service delivery to the client (Austin and McClelland, 2002).

Case management is thus in a crucial position in care arrangements being the mechanism designed to achieve both the move away from institutional provision and the strengthening of home based care. It is the point at which welfare objectives and resource constraints are closest together. Therefore case management has a pivotal role as the setting where the integration of social and economic criteria must occur at the level of service provision, where the balancing of needs and resources, scarcity and choice must take place (Challis, 1992b). It should not be seen as a panacea (Callahan, 1989) for the ills of community care, but rather a particular device which, dependent upon the manner of its implementation, offers a means to manage some intractable policy and practice dilemmas. Much is therefore dependent upon the coherence, form, style and structure of the case management processes implemented to effect community care changes in many countries.

**Defining Case Management and Intensive Case Management**

As noted, the origins of case management lie in the need for coordination of a range of support, provided from a range of sources to achieve a common goal of effective care and support. It arose in response to the shift in the balance of care away from institutional to community-based provision, reflecting the particularly fragmented care services in community care. It can be most simply defined as a strategy for organizing and coordinating care services at the level of the individual client/patient. It has proven applicability to older people with dementia (Eggert et al., 1990; Challis et al., 2002b, 2009). It is particularly important to
make a distinction between different levels of case management or care coordination. Whilst many descriptions of community based support services have used the term ‘case management’ to refer to their activities and contribution to care coordination, this should be distinguished from a qualitatively different phenomenon, Intensive Case Management.

A definition of intensive case management (ICM) can be found in the presence of several features as shown in Box 1. This offers an approach suitable for the community-based care of vulnerable people with chronic conditions. ICM is designed for vulnerable people with complex and fluctuating needs often requiring a multi-service response rather than those with less complex needs which are often met by a single service response provided by one agency.

**Box 1: Features of intensive case management**

- **Core tasks**: case finding and screening; assessment; care planning; monitoring and review
- **Functions**: coordination and linkage of care services
- **Goals**: providing continuity and integrated care; increased opportunity for home-based care; make better use of resources; promote well-being of older person
- **Small caseloads**: to permit attention to fluctuating need and risk; titrating resources to needs
- **Target population**: long-term care needs; multiple service requirements; risk of institutional placement
- **Differentiating features of long-term care**: intensity of involvement; breadth of services spanned; lengthy duration of involvement with older person
- **Multi-level response**: dual function of ICM in coordinating care at user level and generate information to help inform service commissioning to develop more appropriate support services

Thus, case management is a model of long-term care, contrasting with short-term interventions as illustrated in Figure 1. This defining feature of case management renders it particularly relevant to the provision of community care for older people with dementia whose need for long-term care is clearly demonstrated by their declining health status, risk and need for carer support.
Increasingly countries are developing strategies for the care of people with dementia which include enhanced care at home, thereby demonstrating the important contribution of case management to such service development. This is, for example, detailed in Dutch, English, French and Irish strategic plans for people with dementia with case management identified as the means to coordinate the necessarily multiple service inputs as an alternative to admission to long-stay establishment (O’Shea and O’Reilly, 1999; Ministry of Health Welfare and Sports, 2008; Republique Francaise, 2008; Department of Health, 2009). In Australia the strategic vision for the development of services indicates the importance of helping people with dementia and their families ‘navigate’ the community care system with provision located within mainstream services, a role akin to case management (AHMC, 2006). By contrast within the Norwegian strategy for people with dementia there is an emphasis on care planning, the development of home care services, and the development of a competent workforce (Norwegian Ministry of Health and Care Services, 2007).

The core tasks of long-term care embodied in case management, detailed in Figure 1, offer an approach suitable for the community-based care of vulnerable people with long-term conditions. Since older people with dementia typically have complex health and social care needs, it is important that agencies have in place procedures and protocols within case management arrangements which facilitate an appropriate level of response, a feature more likely to be associated with a differentiated approach to case management. This is an approach in which a distinction is made between older people with complex needs often requiring a multi-service response and those with less complex needs which are often met by a single service response provided by one agency (Hughes et al., 2005). However, such a degree of differentiation has not always been present. In England for example, little progress...
was made in the development of a differentiated approach to case management immediately after the introduction of the community care reforms (Huxley, 1993). Rather, case management services were, in the main, provided for the majority rather than for a selected group of older service users (Challis, 1999). It was also apparent that intensive case management, an important component of a differentiated approach, was rare within older people’s services (Weiner et al., 2002). The purpose of intensive case management is to permit more flexible responses through improved co-ordination and appropriateness of care by use of a designated case manager, and is a prerequisite for the provision of complex packages of care to enable older people with dementia to continue living in their own homes (Applebaum and Austin, 1990; Challis, 1994; Challis et al., 2001).

A model of case management that can successfully support older people with dementia at home has been proposed using eight standards of good practice that include intensive case management (Hughes et al, 2005). Four of these relate to the framework within which case management is undertaken:

- provision by specialist multidisciplinary teams
- integrated arrangements for commissioning domiciliary and respite services
- joint financial arrangements facilitating health and social care provision, and
- organisational arrangements promoting a differentiated approach to ensure an appropriate level of response.

The remaining four are associated with the process of case management:
- a continuing targeting process to ensure a level of response suitable to a person’s needs
- a multidisciplinary assessment process appropriate in terms of content and timing
- care planning which supports and enhances quality of life, and
- sufficient monitoring and review to ensure adjustments to care plans occur when required (Hughes et al., 2005; Abell et al., 2009).

2. The Evidence base for case management – UK examples

*Case management in Social and Health Care*

Findings from intensive case management studies have revealed that it is an approach which has a utility in a number of settings. With regard to intensive case management findings are reported from four studies conducted by the Personal Social services Research Unit.

- In social care settings, in Kent and Gateshead, intensive case management reduced the need for care home admissions of vulnerable elderly people to a significant extent. There were also marked improvements in the levels of well-being of elderly people and their carers and these were achieved at no greater cost to the social services, NHS or society as a whole (Challis and Davies, 1986; Challis et al., 2002a).
- In Gateshead a pilot health and social care scheme was developed around primary care incorporating inputs from a nurse case manager and part time junior doctor also demonstrated a reduced rate of care home placement (Challis et al., 2002a).
- Case managers employed by the social services authority were members of a geriatric multidisciplinary team in the Darlington study. Here intensive case management
demonstrated improvements in the well-being of elderly people and a lower level of carer stress were observed for those receiving this new service compared with patients in long-stay hospital care. These gains were achieved at a lower cost than was normally expended upon such patients, reflecting the higher cost of hospital care compared with other institutional settings (Challis et al., 1995).

- Within the Lewisham study a similar case management approach for older people with a diagnosis of dementia was developed in a community based service for mental health of older people by local authority case managers. Here intensive case management appeared to increase the probability of remaining at home in the second year of support compared with existing services. There was evidence of improved well being for the older people and more markedly so for the carers receiving the intensive case management support although the costs were higher than for those receiving traditional forms of support (Challis et al., 2002b, 2009). This specialist scheme was successful in providing care to older people with dementia to enable them to remain at home rather than enter long-term care and provided effective support to their carers. This approach is consistent with other UK and international evidence relating to the provision of specialist care for older people with dementia (Chu et al., 2000; Eloniemi-Sulkava et al., 2001; Minkman et al., 2009). Moriarty and Webb (2000) have also noted factors that could optimise care for people with dementia and their carers. These included responsive case management systems, effective monitoring systems, and home care and day care services sensitive to changes in an individual’s care needs and which provide practical support to carers. The latter is particularly important since the centrality of support for carers remains a constant theme (Moriarty, 1999; Brodaty et al., 2005; Gaugler et al., 2005; HM Government, 2008), and national and international policy has endorsed this approach (AHMC, 2006; Republique Francaise, 2008; Department of Health, 2009).

**CM in Long Term Conditions**

Case management has also been employed as a vehicle for the support of people with long term health conditions, with one of the core goals being reduced acute hospital bed usage. In the UK there is less evidence for effectiveness, with this being a relatively new development (Department of Health, 2004, 2005). It would appear that although patient and carer satisfaction may improve, the evidence that case management for patients with complex long-term conditions contributes to outcomes such as reducing hospital admission, length of stay and improving patient well being is equivocal (Hutt et al., 2004; Singh, 2005). Some studies of case management interventions both in the UK and elsewhere have reported significant reductions in emergency admissions, other hospital admissions or bed days (Huws et al., 2008; Bird et al., 2007; Patrick et al., 2006; Lyon et al., 2006; Leung et al., 2004; Landi et al., 1999; Bernabei et al., 1998). However other studies including the major evaluation of the Evercare demonstration in England (Gravelle et al., 2006) and a large randomised control trial of an integrated system which included case management (Béland et al., 2006) did not demonstrate significant reductions in inpatient care or hospital days. A review of nurse case management interventions which identifies the importance of the context and content of case management interventions can be found in Reilly et al. (2009).
3. Factors associated with success in Case Management

As noted earlier, there are distinctively different models as to how case management may be operationalised with emphasis on different sets of arrangements. It is important to identify and specify these in the design of case management programmes.

Most studies of ICM have focussed upon populations with a high probability of admission or readmission to hospital or long term care settings. It is possible to infer some common elements associated with better outcomes for case management services. These are shown in Box 2.

**Box 2: Case Management factors associated with positive outcomes**

- **Integrated programme funding** – to reduce perverse incentives that can arise from narrow budgetary confines permitting effective integrated teams
- **Logical linkages between model of care, objectives of programme and practice level incentives** – so that the day to day world and pressures of practice remain congruent with the overall objectives (eg capacity to permit flexible response)
- **Clear service objectives with clearly articulated values** – offering a basis to manage and monitor programmes in terms of needs of recipients, service process such as costs and outcomes such as hospitalisation, community tenure or quality of life
- **Precision and clarity of target population** – so that case management is directed upon those for whom it is most appropriate
- **Continuity of involvement** – with staff staying responsible for assessing, monitoring and reviewing cases and gaining feedback from effective and ineffective strategies both at the individual level and more generally
- **Adequate service networks** – in the absence of a local service network intensive support at homes and choice are difficult to achieve
- **Flexible resources and responsive services; case manager influence upon services** – these may be devolved finance; case manager held personal budgets to permit creation of personalised responses
- **A single point of access** – offering uniform assessment and case management (organisational rather than geographic) and clarity about eligibility

Source: Challis 2003; Kane 1999

In addition, it is important to identify the issue of programme fidelity. Case management programmes may develop and change as they are implemented and may thus stray from the combination of factors which contribute to successful outcomes. Managers and commissioners need therefore to view the importance of programme fidelity where the content of the intervention needs to be related to the precise goals it is designed to achieve (Challis, 2003). In the absence of this a variety of forms of case management are likely to continue to develop, not necessarily of proven efficacy.

A recent development in a number of jurisdictions has been the development of consumer directed care, expressed as personal budgets in the UK (HM Government 2008). The development of the two elements of choice and control are key in this approach. However, it is equally clear that take up of such payments is less common amongst frail older people than younger disabled groups. Indeed a national evaluation indicated poorer outcomes for older...
people than other groups (Glendinning et al., 2008). Reflecting this, what has begun to emerge is a spectrum of responses ranging from giving the funding to the individual to personally manage support and services directly, to using a designated representative to plan support and manage needed services. At the latter end of the spectrum there is good evidence that case managers with flexible budgets can achieve good outcomes for frail older people (Challis and Davies, 1986; Challis et al., 1995, 2002a, 2002b, 2009).

4. Conclusions

It is evident that case management is a response to the complexity and fragmentation of health and social service delivery systems (Austin and McClelland, 2002). While there are common components, the practice of case management necessarily varies by setting. Although case managers assist with locating and coordinating services, the range of services they can coordinate and the options that are available will vary widely, depending on the setting in which case management is delivered, funding arrangements and staff skill mix. Such factors need to be clearly articulated in the design of case management arrangements and systems. Key factors discriminating case management arrangements were identified in a review for the Department of Health in 1994 (Challis, 1994). These factors are pertinent in producing a case management model which is coherent, replicable and transportable and are shown in Table 3.

The interdependence of how the work of individual case managers operate at the front line and the structures, settings and arrangements of case management is particularly important. Clearly financial arrangements and the settings in which case managers are located may unintentionally set parameters for what is possible and perceived as reasonable by staff. Other conflicts are inherent in the job itself. While individual case managers are likely may operate from a stance focused on the needs of individuals and their carers they will also be responsible for monitoring and controlling service utilisation (Challis, 1992b). They can also be responsible for making referrals to and authorising a range of community services.

One area of ongoing discussion related to this is the independence of case managers, both clinical and financial. The debate concerns the extent to which case management should be separated from the direct provision of services (Austin and McClelland, 2002). A case manager who is not independent from a hospital, home health agency, nursing home, or community-based service provider may experience a conflict of interest which affects their capacity to develop care plans that fully reflect the client’s interests. Hence case managers can face ethical dilemmas when their role creates conflict between advocating for clients and functioning as an agent for the delivery system that employs them (Browdie, 1992). This is potentially the case in the Japanese Long Term Care Insurance System where individual case managers are employed by different service providers (Ikegami, 2008). However, an alternative perspective is that bringing this scarcity and need dilemma together through public sector resource allocators can make these conflicts visible and transparent even if necessarily uncomfortable (Challis, 1992b).
Box 3: Key Features of Case Management Development

<p>| | |</p>
<table>
<thead>
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<tbody>
<tr>
<td>1.</td>
<td>Definition of the nature, structure and goals of case management</td>
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<tr>
<td>2.</td>
<td>Influence of external contextual and environmental factors</td>
</tr>
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<td>3.</td>
<td>Target population, including user group; targeting methods including assessment</td>
</tr>
<tr>
<td>4.</td>
<td>Case Management as Process and Intensive Case Management; the balance between these two activities?</td>
</tr>
<tr>
<td>5.</td>
<td>Location of Case Management; SSD, NHS, external; access to NHS staff.</td>
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<td>6.</td>
<td>Style of Case Management; administrative or more extensive?</td>
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<td>7.</td>
<td>Operational Aspects of Case Management; role specificity; balance of activities between assessment and review; caseload size; continuity; documentation</td>
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<td>8.</td>
<td>Influence over providers; devolution of Budgets; range of service mix</td>
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<td>9.</td>
<td>Management of Case Management; quality assurance; supervision; peer group review</td>
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<tr>
<td>10.</td>
<td>Clarity of Organisational arrangements; practice incentives; logical links between values, goals, case management service</td>
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</table>

Source: Challis (1994)

From this brief summary of issues relating to case management there emerge a number of research questions or areas of enquiry in relation to case management and dementia care:

- What are the costs and benefits of managing and basing case management in one organisation rather than another? (Primary care Health setting; Secondary health care setting; social care/social services organisation; Not for profit organisation)
- What setting should case management be located in (costs and benefits?) (e.g. Stand alone organisation mono disciplinary; multi-disciplinary team)
- What are the implications of different settings for effective targeting of case management upon the most appropriate sub group?
- What degree of control can case managers have over resources? These can range from low to high e.g. a) Referral; b) Allocative authority c) Budget control at the micro level (per case)
- How do these different elements of resource management influence performance of case management, quality of care and outcomes?
- What are the costs and benefits of different models of delivering case management?
- What are the characteristics of the people with dementia and their carers most likely to benefit from case management support?
Case Management: Aspects of Organisational and Economic Context

Professor David CHALLIS

STRENGTHS

- Effective Coordination
- Continuity of care
- Single point of access

WEAKNESSES

- Case management without resource control is ineffective
- Poor service networks for case management
- Lack of clarity of case management role

OPPORTUNITIES

- Clear targeting
- Better use of resources, enhanced quality of care
- A more coherent care pathway

THREATS

- Loss of clarity over purpose
- Lack of clear service objectives
- Slippage of target group, purpose through time (Programme fidelity)
BIBLIOGRAPHY


Dennis L. KODNER, PhD, FGSA is an expert on public health and aging who is well-known for his work on integrated care systems, care management, and health care innovation for the elderly and other populations with chronic, medically complex, and high-risk conditions. He is founding Director of the Center for Gerontology & Geriatrics at New York Institute of Technology (NYIT) in Old Westbury, New York, USA and Professor of Medicine & Gerontology at New York College of Osteopathic Medicine of NYIT.

Dr. Kodner currently holds adjunct faculty appointments as Professor of Geriatric Medicine at McGill University in Canada and Associate Professor of Health Care Studies at Maastricht University in the Netherlands. Prior to joining NYIT, Dr. Kodner served as Professor of Urban Public Health at Hunter College of the City University of New York (CUNY), The Rose Dobrof Chair & Executive Director of the Brookdale Center on Aging of Hunter College, and Co-Director of the New York Consortium of Geriatric Education Centers.

Before becoming an academic, Dr. Kodner held several senior health care management posts—including Chief Executive Officer, Chief Operating Officer, Chief Innovation Officer, and Chief Planning Officer—at a medical center, “continuum of care” health system, managed care plan, and geriatric center. He is especially well known for his pioneering work as the CEO of Elderplan, Inc.—the nation’s first Social/Health Maintenance Organization for the elderly.

The author of over 300+ publications, Dr. Kodner frequently consults and speaks throughout the Americas, Europe and Asia. In the United States, he has advised the Department of Health & Human Services, Department of Veterans Affairs, Agency for Health Care Research & Quality, Medicare Payment Review Commission, and Congressional Office of Technology Assessment. He was a Special Advisor on Long Term care to the World Health Organization (WHO).

A Fellow of the Gerontological Society of America (GSA), Dr. Kodner is a member of the leadership of the International Network of Integrated Care (INIC) and also serves on the Editorial Board of the International Journal of Integrated care (IJIC). Dr. Kodner is also a recipient of the prestigious Key Award for Leadership in Gerontological Health Policy, Practice, Education and Research given by the American Public Health Association (APHA).
Case Management: 
Organizational and Economic Context

Dennis L. KODNER, PhD, FGSA+

Professor of Medicine & Gerontology and Director, Center for Gerontology & Geriatrics, New York College of Osteopathic Medicine of New York Institute of Technology, Riland Academic Health Care Center

I RATIONALE, DEFINITION AND OUTCOMES OF CASE MANAGEMENT

The dramatic growth in the prevalence of chronic illness—coupled with population aging—calls into question the ability of existing systems of health and social care to adequately meet the complex, multiple and costly needs of increasing numbers of vulnerable persons with long term and disabling conditions requiring ongoing, coordinated support in order to minimize, restore or compensate for loss of physical, cognitive and/or mental functioning.

Irrespective of cross-national differences, evidence strongly suggests that a poor “fit” exists between vulnerable clients and existing systems of care. Services are often disjointed and poorly coordinated, outcomes and quality are sub-optimal, and care is frequently characterized by inefficiency and difficult-to-control costs. This situation is due largely to the plethora of jurisdictions, institutions and providers involved in the care enterprise, as well as the separate funding streams and budgets, conflicting regulations, and clashing organizational and professional cultures that one frequently encounters. The overall result is a service maze which is difficult to navigate, lacks critical information at the client and service levels, demands considerable time to access and receive needed care, responds slowly to crisis, is insensitive to consumer needs and preferences, yields less than optimum quality, and exacts daunting human and financial costs.

There are a myriad of terms used in the health care and social service fields to refer to the coordination or integration of multiple services on an ongoing basis, the most popular of

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1 Adults with Alzheimer’s Disease and related dementias share a great many problems with persons afflicted by other complex, disabling conditions. These include difficulties related to everyday functioning and the prevention of crises; problems with arranging care, coordinating services, and navigating systems; maintaining ongoing physician involvement; inappropriate or excessive service utilization; caregiver strain; and, sometimes even high out-of-pocket costs for uncovered services (as in the U.S.)

2 In the health care system in general and in medical-related settings more specifically, clients are often referred to as patients.

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which are case management, care management, and care coordination. The terminology can be overlapping, definitions change, and they are frequently used interchangeably. Therefore, in a sense, case management is like a Rorschach test.

For our purposes, then, case management is the comprehensive, systematic, proactive process of planning, arranging, coordinating and monitoring multiple health and social services and related care across time, setting and discipline for the individual client who has complex needs and disabilities over an extended period of time. This definition is in keeping with a great many similar definitions proposed by international experts over the years.

Because of the critical role that case management plays in rationalizing care, it has become the centerpiece in today’s integrated care systems. The six (6) most frequently mentioned goals of case management are to:

- Promote comprehensive, holistic care;
- Ensure access to, and the utilization of, services—particularly in home and community settings—appropriate to the needs of a particular client;
- Prevent inappropriate institutionalization and hospital use;
- Develop the capacity of service providers and social networks to promote client independence, well-being and quality of life;
- Enhance the effective and efficient allocation of resources, including coordination, continuity, and cost control; and,
- Facilitate the development of a better and broader array of services, including care that is more sensitive to consumer preferences.

In the peer-reviewed literature, countless case management models have been described, debated and evaluated to a greater or lesser extent. Research generally shows that multi-problem clients with various complex, long term, chronic, disabling, and high-risk conditions do benefit from case management-like interventions. Some of the more positive outcomes of case management are reduced hospital and nursing home utilization, enhanced quality of life, improvements in prognosis, well-being and quality of care, and the prevention of family “breakdown.” While case management may produce cost savings, the evidence is equivocal; the business case for such programs has yet to be firmly established.

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3 “Integrated care,” according to Kodner & Spreeuwenberg (2002), represents a coherent set of methods and models on the funding, administrative, organizational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors to enhance quality care and quality of life, consumer satisfaction and system efficiency for clients with complex problems cutting across multiple services, providers and settings. Case management is a critical integrated care tool.

4 The organizational and economic factors addressed later in the paper surely exert a major influence on cost outcomes and also contribute to the business viability of case management programs.
II PRACTICE PARAMETERS AND VARIABLES IN CASE MANAGEMENT

Although there are many different approaches to performing case management, both literature and practice point to a broad consensus on core components or tasks and their sequencing. However, unlike the strong consensus surrounding these basic functions, there is less agreement as to the best way to structure and operationalize case management programs. This is, in part, related to the lack of an established, empirically-grounded typology/taxonomy. Nonetheless, the following nine (9) variables are believed to be especially relevant in shaping the design and operation of effective programs: (1) mission and program goals; (2) client targeting; (3) caseload size; (4) practice arrangement; (5) staffing and skill mix; (6) organizational sponsorship and location; (7) nature and degree of provider influence; (8) financing and payment; and, (9) quality standards. Variables 7 and 8, which are discussed below, are considered important organizational and economic levers of case management.

III ORGANIZATIONAL AND ECONOMIC CONTEXTS OF CASE MANAGEMENT

While case management has the capacity to improve care, it shares with other forms of coordinated or integrated care a lack of certainty with respect to which bundle of methods, techniques, structures and incentives yields the best results. That being said, observers—including this author—believe that case management models tend to do a better job when they are to some degree consolidated or integrated with, and embedded in, networks or service systems and also more or less exercise control over the financing of care. Therefore, it is important to understand the two main organizational and economic factors intrinsic to achieving success in case management.

Nature and Degree of Provider Influence

The ability to influence and direct the provision of care—including the nature and degree of control over resources needed by the client—play a critical role in the delivery of appropriate, quality, cost-effective care in a case managed environment. In the “brokerage” model, case managers merely make requests to providers, but have little power over the delivery and/or coordination of services themselves. The model can be enhanced by formal referral and service agreements which can assist in strengthening communication and cooperation among and between case managers, provider agencies, and professionals, as well as in promoting more client-centered service provision; this is frequently referred to as the “liaison” model. However, there are more powerful approaches. Included under this rubric are “gatekeeping” programs which are responsible for controlling service access through the purchasing of covered services and/or control over service funds, and more consolidated models which combine various aspects of funding, organization, delivery and coordination of care either through a network arrangement or “under the roof” of a single, fully integrated managed care organization. Increasing international attention is being given to both network and managed care approaches because of promised improvements in inter-agency and inter-professional collaboration, service integration, and cost control.

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5 The following seven (7) activities define case management as a process: 1) outreach and case-finding; 2) screening; 3) comprehensive assessment; 4) care planning; 5) service arrangement; 6) monitoring; and, 7) reassessment and adjustment of the care plan. While not core functions, direct service provision (e.g., nursing care), client/family education and counseling, and advocacy are often found in case management programs.
Financing and Payment

How covered health and social services get paid for in case management programs should also be a critical concern for policy-makers, planners, and program managers. Fragmented service delivery partly reflects fragmentation in the financing of care. Case management has always been envisioned as a partial antidote to financing-induced coordination and continuity problems. However, it cannot produce totally integrated care without the concomitant integration of funding sources. Two main approaches are available to tackle the financing/service integration dichotomy: 1) pooled funding; and, 2) prepaid capitation. With pooled funding, health care, social service and other funds from various sources are bundled by the case management program to create a single funding envelope, joint budget, and aggregate caseload funding formula. With prepaid capitation, a managed care organization or similar entity receives a fixed, prepaid sum for each client “enrolled” or rostered in the program irrespective of the services used by that person. These funds are used to pay for a comprehensive package of services. Because of the emphasis on cost-effectiveness, case managers in capitated case managed programs—whether fully or partially capitated—have greater control over services than in less consolidated or integrated models. While it is unclear how the fixed funding inherent in this financing/payment modality affects case manager decision-making, experience suggests that effective mechanisms can be developed to prevent the specter of adverse behavior or consequences.

IV OPTIONS ON THE CONTINUUM OF CASE MANAGEMENT

Table 1 presents a continuum of options for organizing and financing case management programs. Moving from left to right, the options presented on the table represent a stepwise progression from lowest to highest in terms of the organizational and economic consolidation of authority, responsibility and control discussed above.

In addition to offering a brief description of each model, the table lists the main organizational and financial features, as well as potential strengths and weaknesses. It is important to recognize that these prototypes are not mutually exclusive, as features of one tend to be found in others. Although these models are theoretical representations, one can find real-world versions in North America and elsewhere; the table identifies actual examples.

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4 Control over existing funding sources, used in gatekeeping models, can also be adapted by case managed networks. However, this approach does not eliminate existing service fragmentation and gaps resulting from fragmented, incomplete financing.

7 The integration of financing with case management is designed to leverage clinical flexibility as well as facilitate the provision of the most appropriate level and type of care in an efficient, cost-effective manner. While pooled budgeting is useful in holding the network and its providers accountable to a single bottom line, prepaid capitation has been shown to be effective in promoting seamless care, encouraging prevention, rehabilitation and downward service substitution, and maximizing scarce resources.

8 Some so-called “partially capitated” case management programs are financed, and have control over, a combination of capitated and fee-for-service funds to cover the cost of covered services for their clients. Whether fully or partially capitated, capitation formulas which are fair to both clients and providers are difficult to develop.

9 The “brokerage” model is not included, as it is considered to be the least-change, least-effective form of case management.

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When case management knowledge, the complexities of dementia care, and the lessons learned from coordinated approaches undertaken in the US\textsuperscript{10} are taken into account, it would appear that some version of the network model appears to be the most suitable pathway to organizing, coordinating and financing dementia care in France. In essence, networking can facilitate the creation of a “virtual” home for people with Alzheimer’s disease and their family carers.

As outlined in Table 1, the network structure represents an innovative partnership between provider agencies. Rather than the complex and very costly construction of a new, separate, single consolidated provider/payer entity as in the case of a managed care organization, network formation—through alliance-building and joint venturing—represents a more flexible process and one that is especially well-adapted to local needs and circumstances. In addition to shared governance and well-defined partnership rules and roles, networks tie together partners through mechanisms such as standardized clinical procedures (e.g., for centralized intake, comprehensive assessment, and ongoing case management and service provision), formal communication protocols and information-sharing systems, and a common funding envelope to pay for and control some or all of the costs of client care. Indeed, experience with the PRISMA-France pilot project suggests that case managed networks can be made part of the relatively complicated French system of health and social care, although various implementation and managerial challenges can be expected; similar stresses and strains occur frequently in partnership arrangements in general.

Networks, even those that seem on the surface to be well-designed and working well from the service delivery and clinical perspectives, can still fail. Their spotty history\textsuperscript{11}, particularly in the health and social service fields, is testament to the difficulties involved in maintaining complex inter-agency and inter-personal relationships. The relatively short “shelf life” of some networks is related to several factors: 1) failure to develop and buy into a shared vision, mission, and integrated culture; 2) poorly defined logic, systems, management, and partner roles; 3) inability to withstand and successfully manage the dynamic environment and pressures of partnership working; 4) persistent lack of trust; and, 5) unequal sophistication and power relationships among partners, particularly those in the hospital and medical care worlds vs. those in social services and other sectors.

V SOME KEY TACTICAL ISSUES IN CASE MANAGED NETWORKS

There are four (4) key tactical issues that should be carefully addressed in designing and developing networks for case managed services:

1) Economy of scale:

One important question is whether there should be limits on the size of the service area (i.e., territory) covered by the network or the number of clients it serves. Neither the literature nor experience seems to offer an answer. While medically-oriented, insurance-driven integrated delivery systems in the U.S.—networks in all but name—

\textsuperscript{10} For example, the Medicare Coordinated Care Demonstration, Chronic Care Network for Dementia Demonstration, Cleveland Alzheimer’s Managed Care Demonstration, and Medicare Alzheimer Disease Demonstration, etc.

\textsuperscript{11} For example, closing down prematurely or failing to continue operations beyond the experimental or demonstration phase.
market to very large regions with hundreds of thousands or even millions of consumers and end up serving panels numbering in the tens of thousands or greater, networks which target the frail elderly tend to be smaller from an economy of scale perspective.\textsuperscript{12} This probably better reflects the much lesser size of, and greater complexity of needs in, these populations-at-risk. Common sense also strongly suggests that territories should be divided into more localized zones or districts to help improve program management, operations, and accountability, facilitate inter-agency and inter-professional collaboration, and provide for the more efficient delivery of services.

2) Financial model:

As already presented in this paper and summarized in Table 1, networks can pursue at least two main financing approaches. In addition to defining a common envelope or basket for case management (i.e., what services are covered by the system), the network could adopt an integrated budget for such services or develop and allocate a pooled budget with the direct involvement of partner agencies. One other option, the prepaid capitation (either “full” or “partial”) strategy used in managed care organizations, can be adapted to the network environment, but the option is considered a particularly complex option for networks to develop and manage. A mandated, single, unified budget which gives the network entity total responsibility for all case managed services and the funds to pay for them is clearly a more powerful option than the process of pooling/joint budgeting. However, partner agencies—in the absence of a strong, publicly sanctioned mandate—are likely to oppose the former because of the loss of traditional prerogatives and controls.

3) Success or failure criteria:

Successful networks, whether in the health and social service fields or other sectors, appear to do better than other networks on the following organizational dimensions:

- **Vision.** That is, partner agencies are committed to a shared vision and mission, feel a sense of “ownership,” and have developed and actively support an integrated culture;

- **Structures, policies and roles.** That is, there are supportive organizational structures, clear operating policies and procedures, and well-defined partner roles and responsibilities;

- **Communication.** That is, partner agencies are able to work through problems by discussion, consultation with one another, and ongoing collaboration;

- **Decision-making.** That is, there is a participatory approach to decision-making throughout the entire network organization, and the leadership encourages input from major players at all levels;

\textsuperscript{12} There is, however, an international consensus on optimum caseload size: from 40-85 clients. While wide variation is often found in caseload size, it is axiomatic that the smaller the caseload size, the easier it is for case managers/case management teams to maintain ongoing personal contact with clients and family careers, individualize care, exercise gatekeeping, and control funds.
• **Management of stress and chaos.** That is, the network and its partner agencies effectively handle the stresses and changes affecting day-to-day operations; and,

• **History of change.** That is, evidence suggests that the network has achieved stability over time.

The above attributes of success should be kept in mind when designing and monitoring the implementation of a network strategy for dementia care. An early warning system should be put in place to identify entities that are failing in one or more of these measures. Errant programs should receive careful attention from both managers and change agents to address the root causes of poor behavior or performance.

4) **Assessment method:**

Only a multi-modal approach can effectively measure and plot organizational performance on an ongoing basis. Potential methods and data sources include:

- **Document analysis:** Corporate protocol, agreements, table of organization, plans, policies and procedures, etc.;
- **Record analysis:** Meeting minutes and other administrative-related records; and,
- **Other methods:** Key informant interviews, focus groups, surveys, and case studies.
## Table 1: Options on the continuum of case management (CM).

<table>
<thead>
<tr>
<th>LIAISON MODEL</th>
<th>GATEKEEPING MODEL</th>
<th>NETWORK MODEL</th>
<th>MANAGED CARE MODEL</th>
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<tbody>
<tr>
<td><strong>Description:</strong></td>
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<td>• Publicly sanctioned and funded entity</td>
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<td>• Publicly sanctioned and funded agency</td>
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<td>• Territorial focus or on basis of user self-referral</td>
<td>• Single point of entry</td>
<td>• Single point of entry</td>
<td>• Enrollment/membership focus</td>
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<tr>
<td>• Provider agency-based, e.g., home care or social service organization</td>
<td>• Territorial focus</td>
<td>• Territorial focus</td>
<td>• Single, fully integrated organization/system</td>
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<tr>
<td>• Uses own staff (e.g., home care nurses and/or social workers) to provide CM service</td>
<td>• Freestanding agency</td>
<td>• Network with defined inter-agency linkages</td>
<td>• Dedicated CM team</td>
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<td>• Logistic approach</td>
<td>• Dedicated CM team</td>
<td>• Dedicated CM team</td>
<td>• Comprehensive IS</td>
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<td>• IS (Information Systems)</td>
<td>• IS (Information Systems)</td>
<td>• Enhanced IS</td>
<td>• Comprehensive, patient-centered approach</td>
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<td>• Administrative approach</td>
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<td>• Formal referral and service agreements</td>
<td>• Formal referral and service agreements</td>
<td>• Joint governance</td>
<td>• Single “owner” with total control over governance</td>
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<tr>
<td>• Informal/unsystematic communication and information-sharing</td>
<td>• Formal/systematic communication and information-sharing</td>
<td>• Horizontal and vertical coordination mechanisms</td>
<td>• Integration of financing, organization, service delivery, and clinical management under the roof of one entity</td>
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</table>
Table 1: Options on the continuum of case management (CM) (cont’d).

<table>
<thead>
<tr>
<th>LIAISON MODEL</th>
<th>GATEKEEPING MODEL</th>
<th>NETWORK MODEL</th>
<th>MANAGED CARE MODEL</th>
</tr>
</thead>
<tbody>
<tr>
<td>• None</td>
<td>• Options:</td>
<td>• Options:</td>
<td>• Financing on pre-paid capitation basis; full or partial capitation depending on service envelope</td>
</tr>
<tr>
<td></td>
<td>-Gatekeeping-only</td>
<td>-Common envelope for CM</td>
<td>• Use of fee-for-service (FFS) or other payment methods for care delivered by outside contractors</td>
</tr>
<tr>
<td></td>
<td>-Control over funds</td>
<td>-Single budget, joint budget or other financial arrangements to cover service costs</td>
<td></td>
</tr>
<tr>
<td></td>
<td>-Purchase of services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strengths and weaknesses:</td>
<td>Strengths and weaknesses:</td>
<td>Strengths and weaknesses:</td>
<td>Strengths and weaknesses:</td>
</tr>
<tr>
<td>• Not difficult to organize and manage</td>
<td>• Ability to control the “who,” “what,” “how much,” and “when” of care</td>
<td>• Partnership structure facilitates inter-agency collaboration and service coordination</td>
<td>• Aligns incentives to promote and reward appropriate, high-quality, cost-effective care</td>
</tr>
<tr>
<td>• Based on fine-tuning of existing relationships and linkages</td>
<td>• Poorly integrated with delivery systems</td>
<td>• Assumes substantial authority, responsibility and control over system</td>
<td>• Closely integrated with physicians, hospitals and rest of medical system</td>
</tr>
<tr>
<td>• Exercises little control over services/service system/costs beyond force of agreed-upon protocols</td>
<td>• Viewed as “outsider” agency</td>
<td>• Subject to pressures of a complex and challenging organizational/managerial environment</td>
<td>• Complicated model</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Time-consuming and costly to build</td>
</tr>
</tbody>
</table>
Table 1: Options on the continuum of case management (CM) (cont’d).

<table>
<thead>
<tr>
<th>LIAISON MODEL</th>
<th>GATEKEEPING MODEL</th>
<th>NETWORK MODEL</th>
<th>MANAGED CARE MODEL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Closest example:</td>
<td>Closest example:</td>
<td>Closest example:</td>
<td>Closest example:</td>
</tr>
<tr>
<td>• PRISMA/Desjardins (Quebec)</td>
<td>• National Long-Term Care Channeling Demonstration (US; 1981-1985)</td>
<td>• PRISMA/Bois-Francs and Sherbrooke (Quebec)</td>
<td>• Program of All-inclusive Care for the Elderly (PACE) (US)</td>
</tr>
</tbody>
</table>

Case Management – 8 & 9, March 2010

FONDATION PLAN
ALZHEIMER

37
Case Management: Organisational and Economic Context

Gatekeeping Model

Dennis L. KODNER, PhD, FGSA+

STRENGTHS

- Ability to control « who, » « what, » « how much, » and « when » of care
- Avoids many complexities of direct service provision

WEAKNESSES

- Poorly integrated with existing health care and social service systems
- Considered unnecessary layer of care
- Viewed as outside entity

OPPORTUNITIES

- Appropriate for top-down, regulatory approach to care

THREATS

- Lack of ongoing collaborative relationships
- Little or no provider « buy-in »
Case Management: Organisational and Economic Context:

**Liaison Model**

Dennis L. KODNER, PhD, FGSA+

- Not difficult to develop, implement and manage
- Builds on existing inter-agency relationships
- Not a threat to provider agencies

**STRENGTHS**

- Informal/unsystematic communications and information-sharing
- Little control over provider agencies/services
- No control over costs

**WEAKNESSES**

- Viewed as easy, first-step approach to case management

**OPPORTUNITIES**

- **THREATS**
  - Poor communications
  - Lack of strong systems (e.g., IS)
Case Management: Organisational and Economic Context:

**Managed Care Model**

Dennis L. KODNER, PhD, FGSA+

**STRENGTHS**
- Single « owner » with total responsibility/accountability
- Aligns incentives to promote and reward appropriate, high-quality, cost-effective care
- Strong integration/cost control

**WEAKNESSES**
- Complicated model to develop, implement and manage
- Costly and time-consuming to build

**OPPORTUNITIES**
- Interest by agencies wishing to consolidate/merge and accept risk-based capitation for delivery of comprehensive service package

**THREATS**
- Poor management
- Inadequate capitation
- Financial risk
Case Management: Organisational and Economic Context:

Network Model

Dennis L. KODNER, PhD, FGSA+

- Facilitates inter-agency collaboration/service coordination
- Assumes substantial control over agencies/services
- Modest cost control potential

STRENGTHS

- Subject to pressures of complex and challenging organizational/managerial environment

WEAKNESSES

- Can build on previous experience with networks in health and social care sectors

OPPORTUNITIES

- Poorly-meshed cultures and misaligned incentives
- Partners unwilling to surrender autonomy
- Lack of trust between stakeholders

THREATS
Shinya MATSUDA, MD, PhD

1960 Born in Iwate prefecture, Japan
1985 Graduated from School of Medicine, University of Occupational and Environmental Health
1985-1987 Clinical resident in UOEH hospital and other public hospitals
1991-1992 Public Health Physician course of National School of Public Health, France
1993 PhD degree from Kyoto University
1993 Assistant Professor, Department of Preventive Medicine and Community Health, UOEH
1997 Associate Professor, Department of Preventive Medicine and Community Health, UOEH
1999 Professor, Department of Preventive Medicine and Community Health, UOEH
2002 Fellow, Royal Academy of Public Health Medicine, UK
1999- Chief researcher of the Japanese Casemix Project

Recent Articles in English
Case Management: Organizational and Economic Context
Lessons from the Japanese experience

Shinya MATSUDA, MD, PhD, FFPHM+

Introduction

The very rapid graying of society is ongoing in Japan. It is estimated that the percentage of population over 65 years old will be over 30% in 2025. Besides this very rapid ageing, the number of births has been decreasing. TFR (Total Fertility Rate) has become 1.34 in 2007.

This demographic change means the increase in users of social and health services and the decrease of tax payers, which requires the Japanese government to re-organize its social security system. In terms of social services for the aged, with fewer children, more women working, and changing attitude toward family responsibilities, the traditional system of informal care-giving is widely perceived as inadequate to take care of the increasing number of the frail elderly. In fact, about 40% of the households with elderly people are now so called “aged households”, that is, single old person’s household or old couple’s household. This situation naturally requires the socialization of care. In 2000 the Japanese government introduced the Long-term Care Insurance as a new scheme for the frail elderly.

In terms of medical services, the increase of aged population means the increase of patients who need medical care. Along with the ageing of the society, the number of patients with cancer, cardio-vascular diseases and other life-style related diseases has been increasing. The recent advance in medical technology has made it possible to save the lives of acute patients, such as ischemic heart disease and stroke patients. As a result, such patients require acute medical care services and then following chronic care services. This situation naturally expands medical expenditures. As our previous study showed, the combination of ageing and advance of medical technology is the main cause of rapid increase of the medical expenditures.

The basis of current health insurance scheme was established in 1961 when the Japanese population was young and average life expectancy was around 66 for male and 70 for female. The situation has changed dramatically. The Japanese government has launched a series of health care reform targeting the aged population. They put particular importance on development of home care services combined with case management system.
Japanese Health Insurance Scheme

Japan’s universal health insurance system, which covers the country’s 127 million population, is segmented according to working status and age. The type of company one works for determines the insurance society to which one belongs and the financial contributions one must make. The health insurance scheme is categorized into three basic groups according to age and employment status; Employee’s Medical Insurance scheme (EMI) for employers and their dependants, National Health Insurance scheme (NHI) for self-employed, farmers, retired and their dependent, and Health Insurance Scheme for the Aged (insured are 75 years old and more). All Japanese are covered by one of these three schemes. Because the Japanese system allows free access, Japanese residents can receive medical services at any medical facilities with 10 to 30% of co-payment.

Historical aspect

Figure 1 shows the former welfare system for the elderly before April 2000. If a frail elderly person wanted to receive welfare services, at first he or she had to apply to the local government (municipal welfare office). After a means test, the local government determined the eligibility and the amount of user fee. If the applied person was evaluated as eligible, he or she could receive welfare services as a kind of placement. Available services were home care services (i.e., home help services, home bathing service, day care health service, short stay service, catering service, lease of home care and rehabilitation equipment) and institutional service in a nursing home. The amount of user fee was depending on the economic status of the applicant family. As the user fee was more expensive than that of medical services for the middle and upper class households, most of them preferred institutionalization in hospitals as a substitute to a nursing home. This kind of hospitalization with a social reason is cheap for the user but expensive for the insurer and the government. One of the reasons for the establishment of LTCI was to solve this problem.

Another problem of the former system is that there was no care management. Especially, the lack of care coordination between medical and social care was a big problem. Usually the social care services monopolize service delivery in each territory, so that the service cost was relatively expensive and that there was little competition for quality of care. In order to realize a cost effective quality services for the frail elderly, the government intended to expand the long term care market with care management system. As the free access system was one of reasons for over-utilization of medical services, it seemed that the government intended to establish a prototype of future health care system for the aged based on LTCI (see below), that is, a network model with gate-keeping by care manager.
Long Term Care Insurance

In 1990s, the traditional system of informal care-giving was widely perceived as inadequate to take care of the increasing number of the frail elderly. There were many scandals concerning care for the aged, i.e., abuse and neglect targeting the frail aged by care-givers who were usually exhausted daughter-in-law and spouses. This situation naturally required the socialization of care and the general population asked for the government to organize more feasible programs.

In order to solve this difficult situation, the Cabinet of Prime Minister Morihiro Hosokawa proposed the increase of consumption tax from 3% to 5%. It was too sudden to be accepted by the general population. Finally the government was forced to promote the welfare services for the aged by other financing methods. In 1995, the German government introduced the Long-term Care Insurance. After the considerable researches, the Japanese government decided to create the Long-term Care Insurance as an alternative of tax based welfare services for the aged.
Figure 2 describes the LTCI scheme (Modified in 2006). The budget of the insurance is based on fifty percent from the general tax and another fifty percent from the premium of the insured. There are two types of insured; the first category of insured who are 65+, and the second category of insured that is between the age of 40 and 64. The first category of insured is asked to pay a premium deducted from pension or direct payment for insurer according to their pension status. In the case of the second category of insured, his or her premium is withheld from the medical insurance premium.

The benefit includes social welfare services such as home help and bathing service, stay in nursing home, as well as the use of medical services such as visiting nurses and institutional care in long term care hospitals. The eligibility process begins with the individual or his/her family applying to the insurer (usually municipal government).

A two-step assessment process follows and determines the limit of benefit. The first step is on-site assessment using the standardized questionnaire. The result of questionnaire is analyzed by an official computer program to classify the applicant into one of 6 levels of dependency or to reject eligibility. The lightest level is “assistance required” which is subject to preventive services; the other five levels are called “care required”. The second step is the assessment conference by health care professionals. The conference reviews the classification made by a computer program by taking into account the descriptive statement plus a report from the applicant’s home doctor.

Each eligibility level entitles the applicant to an explicitly defined monetary amount of services. The recipient has to pay 10% of the cost as co-payment. Theoretically, users are free to choose services, but in reality, the care-manager who constitutes a care plan and a weekly time schedule of services, intervenes in this process and co-ordinates the services for the applicant.
Main objectives of LTCI are the de-medicalization and de-institutionalization of care for the frail aged. In 2000, 600,000 aged were institutionalized, and 1,240,000 aged received home-based Activities of Daily Living (ADL) care services on monthly basis \(^5\). On monetary base, these figures correspond to 194.0 billion yen (1.94 billion USD; 100 yen = 1 USD) to institutional care and 99.6 billion yen (1.00 billion USD) to home-based care in each month\(^5\). Six years later, in 2006, the monthly average number of aged persons who received institutional care and home-based care increased up to 810,000 and 2,570,000, respectively \(^5\). On monetary base, these figures correspond to 206.3 billion yen (2.06 billion USD; 100 yen = 1 USD) to institutional care and 228.9 billion yen (2.29 billion USD) to home-based care \(^5\). Even though the home care has been much advanced, the government considers there is still a room for promotion of home care. Thus the government has launched a series of programs in order to expand the community care services and to strengthen the care management system.

**Care managers as a key person of LTCI scheme**

In policies concerning integrated care for the disabled elderly, care management has become an important topic for consideration. Standardized care, continuity of care, flexibility of care, and finely tuned co-ordination between the different kinds of care providers are central parts of care management in order to realize high quality care for the disabled aged and to enable them to continue to live independently in their own homes for as long as possible. This is the most important reason that the Japanese LTCI scheme has formalized the care management process.

**Figure 3  Care management under the LTCI scheme**

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*Case Management – 8 & 9, March 2010*
A care manager is entrusted with the entire responsibility of planning all care and services for individual clients (Figure 3). According to the results of needs assessment of the client and his or her wish, a care plan is drawn up. The care manager organizes the care specified in the care plan and works with the client, supervises and evaluates the care process (monitoring). When necessary, the care plan is adjusted. It is very important to know that a care manager has an ability to decide the type and volume of services under the individualized budget envelop corresponding to eligibility level. This financial authority makes them possible to negotiate with service providers.

In this way the care manager plays a pivotal role in the LTCI scheme. The LTCI fund pays a fee of care management for each care manager (3,000 – 13,000 Yen per month per each case: = 30 – 130 US$; 1 US$ = 100 Yen).

The introduction of LTCI has changed the balance of authority in the health care market. Traditionally physicians have always played a key role in the authority and have influenced the care process of the frail elderly. However, the introduction of LTCI has changed the balance of authority from the physician to the care manager. This shift in authority requires skill in conflict management for each care manager, because he or she is often confronted with the problem of co-ordination among different care providers who do not always believe the authority and ability of care manager.

Another important point is that a care manager system has introduced a kind of gatekeeping into the Japanese health care system that has long been based on the free-access concept. It is also important that LTCI realized a prefix payment scheme. Under the medical insurance scheme, it is the physician who determines the type and volume of services. As the Japanese medical insurance system adopts the fee-for-service system with no budget limitation, there is a risk of over-utilization. The gate keeping and budget control by care manager is expected to rationalize the use of care services for the aged.

**Importance of Dementia care**

MHLW estimates that there will be 3.4 million of dementia elderly in 2035, twice more than in 2005. As the dementia elderly require more resources of medical and social care services, it is an important problem for the government how to establish a new social system for them.

According to the results of our research on factors associated with aggravation of dependency level among the frail elderly, dementia was detected as one of the significant risk factors. Furthermore, our research suggested that quality of care management could prevent aggravation of dependency level. Quality assessment of care plan for dementia person is now one of the hot topics of researches in Japan.

Traditionally, the dementia persons have been treated in institutional services, such as psychiatric wards and nursing home. But the rapid increase of dementia persons makes it impossible to treat all of them in the institution. We have to prepare good quality community services for the dementia persons. Without enough volume of community services for the dementia persons, it is not possible to practice the good quality care management. It is also important to organize the flexible system which makes it possible for the dementia cases to use institutional and community services according to their condition. This requires a good care management system.

The previous researches have clarified effectiveness of fine tuned day care services, physical fitness class, memory training class and etc. MHLW has launched a project to
summarize evidences for prevention of aggravation of dementia. These evidences are planned to be used for the guideline for better care management.

**Conclusion - Lessons from the Japanese experience –**

There are many similarities between French and Japanese health system; i.e., free access, universal social insurance system, mentality of medical profession, fragmentation of services, poor coordination between social and medical care. Therefore, it seems that the Japanese experiences will be suggestive for the French policy makers and researchers.

**Financing for care management**

In order to solve the problems of poor coordination among the services, we have introduced the care management system, first in LTCI scheme and then medical insurance scheme. The official tariffs were set for care management services for care managers in LTCI and liaison nurses in medical insurance scheme. Additional tariffs are set for the care management of dementia case. There is a critic that this tariff is not enough. However, the implementation of care management in public insurance scheme is an important step for future. It will change the power balance. Too much medicalization of care for the aged is one of the most important problems in the Japanese health system. It is not cost effective and not comprehensive. It was very important to establish a status of nurse and social worker as a care coordinator and gate keeper into the official health system for elderly.

**Network model**

According to the definition of Prof. Kodner, the Japanese care management model will be a network model or mixture of network and liaison model. Considering the historical background of our health system, this model seems to be the most acceptable one. As the Japanese health service delivery system has been developed by the private organizations, it has been relatively difficult to establish collaboration among them. The health insurance fund is a non-profit organization and addicted by too much bureaucracy, thus they do have little incentive for efficiency. In this situation, managed care model is difficult to be accepted in Japan.

At the present time, the network model seems to work relatively well under the LTCI scheme. It does not seem so much difficult to construct a network among the co-medical and social service providers. However, it is a problem how to integrate the medical services (esp. physician services) into the network in order to integrate medical and social care services under the same roof.

Furthermore, we have to develop the IT system for sharing client’s information in order to make it possible to more efficiently deliver integrated community care services by different service providers. As the government has been reluctant to determine the national format of health information system, today there are wide variations in formats of electronic health record (EHR) system in Japan. Most of health institutions have their own EHR but they cannot share the information. We are now doing a social experimentation for common EHR system in a city of Kyushu Island under the collaboration with local medical association in order to establish a prototype for future network system (Figure 4).
**Integration of housing policy**

The network model requires a good (strong) care coordinator and enough volume of community services. In fact, the volume of community health care services has been increased after the introduction of LTCI scheme. However, as the Japanese government has not implement the housing policy as a social security policy, vulnerable groups, such as poor elderly, face difficulty of having good quality residence. This situation makes it difficult for care manager to organize community care for the aged, especially for the dementia aged.

In order to solve this problem, the government tries to implement the special residences for the dementia persons, i.e., group home and multifunction small institution for the aged. However, the volume of such services is still lacking. It is very important to integrate the housing policy into health services for the frail aged, especially for the dementia aged.

**Integration of medical and social services**

At the beginning, in order to avoid the conflict with medical professionals, the government has introduced the care management system in LTCI scheme (social services). Naturally, the care for the aged, especially for dementia aged, requires both of medical and social services. Therefore, at the second step, we have to integrate the care management system. In order to realize it, we have to strengthen the authority of care manager.

As the payment for care management by social insurance is not enough, most of the Japanese care managers employed by various care service providers such as day care centers, home help offices, home nursing offices. Therefore, they sometimes suffer from ethical dilemmas when they have to balance the two roles as an advocate of client and as an agent for service providers. This situation must be ameliorated.

Kumamoto City Medical Association: more than 500 patients are covered (June 2009)
The Japanese government has developed medical services and social services for the aged separately. Along with the rapid graying, the government is required to develop an integrated system for the frail aged. In 2012, the modification of system is planned. Integrated care, community care and care management are keywords.

**Research questions**

- Costs and benefits of care management under the different models.
- Key success factors of care management for the dementia person.
- Assessment methodology.
- Sociological study of care management (factors for acceptance by clients and their family)
- International comparative study of care management
REFERENCES

4) Matsuda S: Health Insurance Scheme for the Aged in Japan – its outline and challenges –, APJDM, (in press)
Jean François DARTIGUES

**Diplomas and qualifications**
1985 PhD in Epidemiology, University of Bordeaux
1981 Qualification in Neurology
1979 Qualification in Rehabilitation and Physical Medicine
1979 Medical Doctorate (MD), University of Bordeaux

**Employment history**
- since 1992

Head of the team « Epidemiology of Brain Aging » at the INSERM department U593
“Epidemiology, Public Health and Development” and then at the Research Centre INSERM U897
« Epidemiology and Biostatistics » since 2008 (director R. Salamon)
- since 1985

**Professeur des Universités-Praticien Hospitalier** in Public Health at the Institute of Public Health, Epidemiology and Development (ISPED) of the University Victor Segalen Bordeaux 2, and at the Neurological of the University Hospital from Bordeaux.

**Main research activities:**
My main research field concerned the epidemiology of brain aging, Alzheimer Disease and related Disorders for more than 20 years, with a particular interest in descriptive epidemiology, risk factors studies and natural history of cognitive decline.

Main responsibilities and grants since 2006:
- Co-principal investigator with P Barberger-Gateau of the PAQUID (QUID sur les Personnes Agées) epidemiological study since its origin in 1987.
- Co-principal investigator with Annick Alperovitch of the Three-City Study since its origin in 1998.
- Principal investigator of the AMI study (cohort of thousand elderly farmers older than 65.

Matthieu DE STAMPA is a geriatrician and a public health physician in Sainte Perine Hospital in Paris. He works in the department of PADIS (Pole Ambulatoire Diagnostic Interventions en Santé) and at the DGS (Direction Générale pour la Santé) as expert assessment for the implementation of the MAIAs (Maisons Autonomie Intégration Alzheimer). He has a Master of Epidemiology from the University of Kremlin-Bicêtre (Paris XI) in 1999, a Diploma of Public Health and a Diploma of Geriatrician from the University of Cochin-René Descartes (Paris V) in 2001 and a PHD in Public Health from the University of Reims in 2008 with a Canadian co-tutorial.
He did a one-year training in integration models of care with Professor Howard Bergman at the Solidage Research Group in Montreal (Quebec) in 2003. His topic is the participation of primary care physician in the SIPA model (System Intégré Personnes Agées). He is researcher associated at Solidage, McGill University - Université de Montréal Research Group on Frailty and Aging Research Group.
He is the co-promoter of the COPA model (COordination Personnes Agées) which was implemented in France in the 16th borough of Paris in 2006. It’s a bottom-up implementation model with a single entry point, an intensive case management with a target population, a two-person team of a primary care physician and a case manager with a support team from the hospital settings.
PROFESSIONAL PRACTICES

Speakers:

- Barbara VICKREY
- Christopher CALLAHAN
- Yves COUTURIER
Barbara VICKREY, MD, MPH, is Professor and Vice Chair of the University of California, Los Angeles (UCLA) Department of Neurology, and Director of the UCLA Health Services Research Program in Neurology; she has been a consultant in the RAND Corporation’s Health Program for 20 years. She led the Translational Research Core of the UCLA Alzheimer’s Disease Center for a decade. She earned her MD from Duke University and an MPH from the UCLA School of Public Health. She received formal training in health services research as a UCLA Robert Wood Johnson Foundation Clinical Scholar and as a RAND Center for Health Policy fellow.

Dr. Vickrey’s research aims to create ways to translate into routine care findings about therapies that have been proven – through randomized trial evidence - to better the health of people with neurologic conditions. She has developed tools to assess quality of care and to measure patient-oriented outcomes such as health-related quality of life, and led research to analyze what components of the healthcare delivery system “explain” why there is low uptake of randomized trial evidence into practice. The goal of these studies is to design interventions that will logically alleviate or circumvent these barriers, then test those interventions in randomized controlled trials to determine whether they lead to higher adherence to evidence-based practices and better health outcomes.

Her initial quality improvement research focused on interventions aimed at changing physician behavior. Working with leadership of the American Academy of Neurology, she led a randomized trial of a successful, opinion-leader led intervention to improve neurologists’ adherence to guidelines for dementia care in New York; results were published in *Annals of Internal Medicine* with an accompanying editorial. Her approach to healthcare delivery interventions to improve quality of care evolved based on these experiences and the literature, toward designing interventions that substantially “re-engineer” how care is delivered. These types of interventions, drawn conceptually from the Chronic Care Model, include as central elements engaging patients in managing their disease, creating strong collaborative networks in care delivery with community agencies providing key patient services, and developing cutting-edge information systems applications to improve coordination and efficiency across these care delivery partners. Dr. Vickrey designed and led a randomized controlled trial involving three healthcare organizations and three community agencies in a novel collaboration that created a “virtual” care system that spanned the medical system and community agencies, created protocols and training for dementia care managers to coordinate care, and established a web-based dementia care management tracking and communication system. Relative to usual care, there were substantial and meaningful improvements both in dementia care quality – as measured by adherence to professional society guidelines - and in outcomes among the 408 pairs of caregiver and...
persons with dementia who were enrolled and followed for 18 months. This study was also published in *Annals of Internal Medicine*, with an accompanying editorial that, based on these findings, called strongly for policy changes in the way dementia care is provided under Medicare nationally.

Dr. Vickrey directs an American Heart Association-funded Cardiovascular Disease and Stroke Outcomes Research Center, which includes research targeting stroke prevention in underserved minority communities. She has published extensively on care and outcomes for epilepsy, multiple sclerosis, and Parkinson’s disease, using a wide range of methodologies. She has led multi-disciplinary teams of health services researchers, clinical researchers, community practitioners, and community agency leadership and staff; her research includes collaborations with public and private healthcare facilities and organizations.

Among her 90 original research publications are articles in *British Medical Journal* and *The Lancet*. She has received funding as Principal Investigator from the National Institutes of Health, Veteran’s Administration, Agency for Healthcare Research and Quality, and multiple state agencies and foundations. Dr. Vickrey has formally mentored over 20 post-doctoral health services research fellows and graduate students from neurology, internal medicine, psychiatry, geriatrics, nursing, and public health. She provides scientific reviewer services for NIH and multiple foundations and over 40 journals across many clinical and health services research disciplines.

In 1998, she was awarded the Alice S. Hersh Young Investigator Award, a major national US award in health services research, from AcademyHealth; in 2008, she received the Researcher of the Year Award from the California Southland Chapter of the Alzheimer’s Association.
From 2001 to 2004, researchers at UCLA designed and executed a cluster, randomized control trial of a comprehensive care management program for dementia (http://www.adc.ucla.edu/access/access.swf). The setting of the trial was three health care organizations in San Diego County in southern California; these organizations provided care for nearly half of all elders over the age of 65 years in this region. The care management program’s primary goals were to improve adherence to evidence-based guidelines for dementia care. Secondary goals included raising or maintaining patients’ health and caregivers’ self-efficacy and social support, and lowering caregivers’ unmet needs for caregiving assistance. The care management program was compared to usual care. Clinics were the unit of randomization. There were 408 patient and caregiver dyads enrolled in the trial and followed for 18 months. All patients were over the age of 65, and more than 95% of study participants were community dwelling (not institutionalized).

The design of this care management intervention evolved from observations and review of the literature about problems with dementia care as delivered in most health care settings in the US. One observation was that many of the evidence-based recommendations regarding dementia care involved treatments or services that were typically available from social service or community agencies, rather than from the traditional medical care system. Furthermore, interviews with both providers in the medical care system and representatives of community agencies providing dementia care services revealed that there was tremendous fragmentation and lack of ability to communicate across those organizations for care of individuals or even for referral. A second observation was that because services such as respite care were often not being offered or not received by care recipients in a timely fashion, many patients and caregivers came into the medical system in crisis situations. Furthermore, social service follow-up was typically limited to the crisis. Yet it appeared that many of these problems, such as caregivers becoming overly stressed, or safety issues, could have been prevented through earlier intervention. Focus groups and interviews reveal that caregivers often report that they are desperate for information about how to manage symptoms and how to prepare for the future as the disease progressed. These kinds of concerns seemed to cross all socioeconomic boundaries, and may reflect that becoming an informal or family caregiver is not something people plan to do but is an unanticipated life event. Finally, there were multiple studies showing a “therapeutic nihilism” among many healthcare providers with regard to the extent to which they perceived they could intervene as medical care providers in the adverse health consequences of this progressive disease.
Given these observations and the existing literature at the time, we based the intervention we designed on the Chronic Care Model, which had been developed in the prior decade by Ed Wagner and colleagues. This model has a number of components including changing care delivery by using multi-disciplinary teams of providers who provide appropriate care in a coordinated fashion, use of information technology to help guide decisions, and use of self management to empower patients - or in this case, their caregivers - to be better informed about how to manage aspects of their condition. The Chronic Care Model posits that with these kinds of changes, and with greater access to and receipt of community resources, patients and providers are pro-actively able to affect care processes in a way that leads to better outcomes. We designed this dementia care management intervention with these central elements:

1. Dementia care managers (primarily social workers) who used guideline-directed protocols to provide care that enhanced and “wrapped around” doctor visit-based primary care.
2. Partnerships of the healthcare delivery organizations with key community organizations that provided social services for dementia patients and their caregivers, with protocols for linkages with those agencies and multi-agency coordination around cases.
3. A proactive strategy for both finding cases of dementia before they were in crisis, and for ongoing follow-up to make sure that those problems that were identified were managed before they escalated or had adverse consequences.

The figure shows the existing usual care for dementia and how this changed in the context of the intervention that was designed. In particular, as noted before, the dementia care managers were a central component of this intervention. They were located not only within the healthcare organizations but also had counterparts at the community agencies. A team of representatives from all of the participating healthcare organizations and community agencies, caregiver representatives from the community, and the researchers who facilitated the process, developed structured assessments that the care managers used to screen for problems. The team also designed guideline-based protocols that the care managers used to act on problems that were identified. The care managers had backup clinical support at their healthcare organizations and used an internet-based care management software system to help them track cases and provide follow-up in an efficient fashion, using automated reminders in the care management system. The care management software system allowed care managers between the healthcare organization and the community agencies to share care plans that were developed for each patient (with the patient/caregiver’s permission). Care managers also trained caregivers in self-management activities such as logs of behavior difficulties, and they engaged in collaborative decision making to prioritize problem, and provided some counseling to caregivers. The extent and intensity of follow up for a given patient/caregiver dyad was guided by the number and intensity of the problems that had been prioritized.

At the time of the ACCESS trial, there were no pre-existing tools or models, and it took about 12 months for the Steering Committee to develop and implement the tools and protocols. At the time, there was also no ready-made information technology system for care management, and a fair amount of research was done to find the system that we used and to tailor it for the project’s purposes.
Practical tasks of the care managers:

1. **Number of people to be supported.**

We have found that the ratio of patient-caregiver dyads to care managers depends on the complexity of the mix of cases. That is, if a group is targeted and identified to be enrolled in care management who are high utilizers of medical care services, then that ratio may be lower. This is because the intensity of the care manager’s effort varies by complexity of the needs and issues that are faced in a particular case. If the goal is to enroll all patients in a healthcare system who are identified with a diagnosis of dementia, then there may be a range of less affected to more affected individuals, and the level of needed intervention may vary. As noted, there was a minimum work-up that all patients underwent, and re-assessments were conducted at least every 6 months. However, the number of contacts in-between varied according to the number, extent and urgency of the problems that the care manager was addressing. We estimated that by steady state in the ACCESS trial, the ratio of patients to care managers was about 50:1.

2. **Relationships with the informal network of the person with dementia.**

We focused on identifying one primary caregiver (usually a family member, although occasionally it was a friend), but the care managers could interact with other family members; this was dependent on the particular situation of the patient. Of note, the frequency of interaction by the end of the 18-month follow-up was a median of one telephone call per month, but there was a wide range. The initial assessment was at the patient’s home, a decision made by the Steering Committee after thoughtful deliberation. The care managers felt that an initial home visit provided them with additional important information that a clinic assessment or a telephone call might not reveal. Most of the subsequent follow up was by telephone, but if a follow-up home visit could be arranged and was felt useful, this was left to the discretion of the care manager. Caregivers and patient were given a binder with selected information and that also included a photograph of the care manager and her contact information. As noted, there was ongoing follow up at least every 6 months and a median of one call per month.

We subsequently have analyzed whether there were characteristics of caregivers or patients that predicted greater benefit from care management. One characteristic was education level of the caregiver; less educated caregivers benefited more from the care management intervention. This suggests that the intensity of the relationship and the frequency of contact had an important role and overcame some disadvantages of lower education among caregivers.

Care managers reported that there were some caregivers who had to be persuaded to undertake certain preventive measures offered by the care manager according to the protocols, such as enrolling the patient in a program of the Alzheimer’s Association to minimize the impact of wandering. While many caregivers embraced all offers of assistance, some felt that until there was a problem, why would they need certain services? We also observed that the care managers (who met monthly) felt that the protocol should be revised so that everyone was placed on a waiting list for respite care at the onset of case management; this way, by the time people needed it they would have moved up the list and be in position to receive it. As noted, the care managers had to learn skills to persuade some caregivers to undertake these “preventive” measures.
3. **Relationships with the professionals involved in the care arrangements.**

One of the most striking findings since we have adapted the ACCESS care model into other healthcare settings is that at times we have had to persuade healthcare organizations that the care managers and the doctors need to sit down together and have regular meetings as a team, in order to adapt the program to their setting. We found that this communication and relationship-building is essential to effectively improving the coordination of care and its quality. In the US, some disease management programs for congestive heart failure and other conditions operate entirely separately by telephone, and do not involve or effectively involve the patient’s providers based within the medical care system. We judged that an essential component of the ACCESS model was that a team was created, which allowed for communication and coordination of care through planning what those care protocols would be and establishing lines of communication necessary to successfully and consistently execute those protocols.

4. **Expected Competencies and Abilities.**

When we designed the study we thought that either a social worker or a nurse could execute the kinds of protocols needed for dementia care. In contrast to certain more “medically-oriented” conditions such as congestive heart failure, much of the work in dementia care delivery revolved around management of behavior and support of the caregiver through connecting them to services in the community or through direct counseling. When the care manager did encounter a medically-oriented issue, such as a possible depression or a delirium, they would refer the patient to the primary care provider (or urgent care) for evaluation and management, according to the protocols. Thus, the care managers needed some minimal training in dementia but not an extensive amount of medical training. However, we did require and felt that they needed to have qualifications of a social worker (or nurse) to successfully carry out ACCESS care management protocols.

Care managers also needed to be able to use technology or be willing to learn it, but they did not have to be technically competent with computers when hired. In fact, one of the ACCESS care managers was not very proficient with a computer when she began. By the end of the study, though, she was the most technologically savvy of all the care managers, because she had seen how valuable using this information technology was for her ability to provide high quality care and to do it in an efficient manner without letting important care concerns get lost or dropped accidentally.

Care managers also had to be oriented toward a preventive framework, rather than a reactive one, but many social workers were used to working in crisis-oriented situations; thus, for some of them, there was a period of time when they had to change from the idea of implementing a short-term solution and limited follow-up, to providing ongoing care management to prevent problems.

5. **Ethical Issues.**

After considerable discussion among the Steering Committee, the decision was made to place the patient/caregiver’s primary care manager within the healthcare organizations. Thus the care managers who conducted the initial assessments had access to the patients’ medical
records because they were providers within that organization. At the time that patients enrolled in the study, they had to have a caregiver, and our study did not address what to do with patients who have no family and need but refuse care; that remains a very challenging issue in any setting.

6. **Best Training and Curriculum.**

As noted, training in use of the care management software was necessary to implement the ACCESS program, as well as training about the care protocols and about dementia in the elderly. From a broader perspective, one substantial barrier at present to any care management program is that there is no simple package for the intervention. These interventions are complex and have to be adapted to each site; in our experience there needs to be some involvement and communication across providers and the care managers to establish a successful program, as opposed to models in which the care managers act completely independently of the care providers.

7. **Other Difficulties or Challenges.**

One barrier is the investment of time to establish a care team to adapt existing protocols into their own healthcare setting. Another barrier is to have the guidance and support to help healthcare organizations successfully adapt and put the program in place in their organization. Our study’s tools are all available on a website, but putting the intervention in place is more than simply downloading the tools: it involves adapting them to a different setting and establishing relationships and communication both internally and externally with community agencies. As well, there is no uniform information technology or one care management software available for this purpose, although there are many more template systems that can be adapted now than were available when we began our study nearly a decade ago. As we have worked with new groups in the Los Angeles area, we are aware of a few additional software systems now available.

We estimate that a start-up period of 6 - 9 months is needed to put these kinds of programs in place in one setting, with researcher guidance. In terms of broad dissemination, if there is considerable variation in systems of healthcare and types of community resources in France, disseminating successful care management programs more widely will take longer than if care settings and resources are more homogeneous.

8. **Perception of the care manager by the users or customers.**

As noted, the care managers had to build relationships with the providers (or representatives of larger provider groups). In the US at present, there are widely-varying cultures and experiences among doctors about working in teams. Part of this is because our systems for paying for healthcare do not involved reimbursement for care managers, so it is rare that physicians are part of a care management team. Geriatrics is a field in which there is more an experience with team-based approaches, but there are relatively few geriatricians and certainly not nearly enough to take care of all patients with dementia.

9. **Unique issues for Alzheimer’s Disease.**

Again, the emphasis on establishing community linkages to provide a wide range of services and support for caregivers and patients is relatively unique for Alzheimer’s disease and
dementia compared to other chronic medical conditions, like congestive heart failure or diabetes. We discussed at some length whether to use caregivers based in the community and not within the healthcare organization; in the end, the Steering Committee felt it would not be likely to be successful unless the care managers were located within the healthcare organizations. We also found that because of the need for community services, the community agencies and the healthcare organizations came to a consensus to share the care planning for the patients, so that multiple community agencies did not have to repeat multiple assessments with the caregiver, who generally are already feeling burdened. Another benefit of this sharing of care plans was that it allowed the community agencies to know what the overall care plan was, and improved efficiency in their delivery of services (as well as less hassle for caregivers and patients).

**Figure**
Once they engage in care management, the vast majority of providers and patients/caregivers are convinced of its value and do not want to go back to the “old” ways of either delivering or receiving care.

There is a growing body of evidence on the efficacy and utility of care management approaches and the factors and context associated with greater benefit.

STRENGTHS

OPPORTUNITIES

Rising dementia prevalence is leading to greater awareness of its societal burden, and is putting pressure on systems to change dementia care delivery.

Greater awareness of the importance of patient-oriented outcomes is fueling interest in healthcare interventions that improve patient and caregiver functioning and well-being.

Rapid growth in information technology advances and information access can be harnessed for more efficient and effective care.

WEAKNESSES

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WEAKNESSES

THREATS

Many undiagnosed cases of dementia exist (for which care management opportunities would be foregone), due to providers' nihilistic beliefs about dementia care.

Financial pressure to target care management to high utilizers may lead to missed opportunities to maximize long-term benefits for earlier stage patients and their caregivers.

Growing regulatory barriers to health services research in general in the US slows progress.
BIBLIOGRAPHY


Christopher M. CALLAHAN, M.D., FACP graduated from St. Louis University School of Medicine in 1985. He completed his Internal Medicine residency at Baylor College of Medicine in 1988 and completed a fellowship in Health Services Research at the Indiana University School of Medicine in 1991. He has a Certificate of Added Qualifications in Geriatric Medicine and his research, education, and clinical interests are in primary care geriatrics. He is a Research Scientist in the Regenstrief Institute, Inc and the founding Director of the Indiana University Center for Aging Research. He is the Cornelius and Yvonne Pettinga Professor in Aging Research. In 1999-2000 he was a Visiting Scholar in the History and Psychopathology Research Program in the Department of Psychiatry at Cambridge University in the United Kingdom. During this sabbatical, he co-authored the book “Reinventing Depression: A History of the Treatment of Depression in Primary Care” (Oxford University Press).

Dr. Callahan is a 1996 recipient of a Paul B. Beeson Physician Faculty Scholar in Aging Award. His research has been supported by the John A. Hartford Foundation, Inc, the Agency for Healthcare Research and Quality, the National Institute on Aging, and the National Institute on Mental Health. Locally, he received the Teaching Excellence Recognition Award at Indiana University in 1997 and the Tony and Mary Hulman Health Achievement Award for Excellence in Health Sciences Research in 1999. Dr. Callahan is a member of the Editorial Board of the Annals of Internal Medicine. Dr. Callahan’s research focuses on strategies to improve the care of older adults in primary care. This research explores patient, provider, and systems-level interventions to enable primary care physicians to deliver excellent care to older adults. His specific research interests include the recognition and treatment of late life depression and the care of older adults with dementia.
Case Management for Alzheimer’s Disease in Primary Care

Christopher M. CALLAHAN, MD

Prepared by:
Christopher M. Callahan, MD
Cornelius and Yvonne Pettinga Professor in Aging Research
Director, Indiana University Center for Aging Research
Scientist, Regenstrief Institute, Inc
Indiana University School of Medicine
Indianapolis, Indiana, USA

Introduction

Dementia is a growing public health problem with the prevalence ranging from 3-11% among people aged 65 and over.\(^2\) Dementia leads to a high burden of suffering and excess health care costs for patients, families, and society.\(^3,4\) Alzheimer disease accounts for 60% of the cases of dementia in primary care settings.\(^5\) By mid-century, estimates suggest that the number of cases of Alzheimer’s disease will increase four-fold to about 10-12 million.\(^6-8\) More than 80% of those afflicted with dementia will be institutionalized before death despite the desire of patients, families, providers, and societies to avoid nursing home placement.\(^9\) Even if we had an important scientific breakthrough or disease-modifying treatment in the next few years, projections still suggest a three-fold increase in the prevalence of Alzheimer’s disease by 2050.\(^7\) In other words, approximately 6 million Americans who have already survived to age 40, and are alive today without Alzheimer’s disease, will require longitudinal care for Alzheimer’s disease over the next 40 years. Even under optimistic scenarios, we must prepare to care for millions of older adults with Alzheimer’s disease. The purpose of this paper is to describe the lessons learned in improving care for older adults with Alzheimer’s disease through the use of case managers in the primary care setting. We first discuss why primary care is an important site of care for older adults. Next we describe our prior interventions using case management in this setting. Finally, we describe the practical realities of implementing case management for Alzheimer’s disease in primary care.
Understanding Primary Care

Primary care is an important site for improving the capacity and quality of care for older adults with Alzheimer’s disease for at least three interrelated reasons. First, there are simply more primary care physicians and they are more evenly distributed across the country. Primary care physicians constitute the major infrastructure element in the care of older adults. There are nearly 10 times as many primary care physicians in the United States than adult neurologists, geriatric medicine physicians, and geriatric psychiatrists combined. In addition to low numbers of physicians with specialty training in the diagnosis and management of dementia, dementia care specialists are unevenly distributed across the country. Second, studies of ambulatory care services utilization among Medicare beneficiaries demonstrate that primary care physicians generate nearly half of all Medicare claims for older adults compared to less than 1% by geriatric medicine physicians. Even among medically complex older adults, primary care physicians often remain the main provider of care. Thus, most patients with Alzheimer’s disease are already receiving their medical care in primary care settings and will remain in this setting even when the severity of their condition worsens. Third, most older adults with Alzheimer’s disease suffer from multiple comorbid chronic medical conditions. Many of these conditions result in functional disability, prescriptions for medications with psychoactive and anticholinergic properties, or other problems which may complicate the care of older adults with Alzheimer’s disease. Given these three realities, it does not appear plausible to significantly improve the care of older adults with Alzheimer’s disease without raising the capacity and quality of care in primary care settings.

Despite the fundamental role of the primary care setting, researchers and policy-makers consistently document suboptimal quality and poor outcomes among older adults receiving the usual care of generalist physicians. In assessing these quality problems, one must consider some of the system-level barriers inherent in the primary care setting. Typically, these barriers have been summarized in terms of time, competing demands, and resource allocations. The typical office visit is 10-20 minutes long and there is little evidence that this has changed substantially in the past half century (nor is it likely to increase in the next). A typical primary care patient presents with 15 risk factors to address and would generate 24 preventive service recommendations. It is estimated that a primary care physician would need 10 hours of each day to deliver recommended care for their patients’ chronic conditions, 7 hours per day to deliver recommended preventive services, and 3 hours per day to complete paperwork. It is perhaps not surprising then that Americans receive only about half the recommended services for acute, chronic, and preventive care. It is also clear that quality of care issues are not limited to dementia and related disorders. Because most primary care physicians care for less than two dozen older adults with Alzheimer’s disease, quality improvement initiatives may place a higher priority on more prevalent conditions such as hypertension, diabetes, coronary artery disease, anti-coagulation, and prevention. Two-thirds of all patient visits in the US are to practices of fewer than four physicians who place a high value on the efficient use of examination rooms. In considering the initiation of case management, one must consider space as a limited resource in primary care. If one imagines a case manager for the multiple other chronic conditions listed above, the primary care practice quickly runs short of office space. Primary care physicians report that they have insufficient time to spend with their patients and feel overworked and dissatisfied. The structural realities of primary care described above are important to
consider as one contemplates quality improvement in primary care and particularly as one considers integrating additional human resources within this setting.

Prior Interventions Using Case Management

There have been three general responses to this persistent quality problem in primary care. The first has been to improve the knowledge, skills, and attitudes of primary care physicians. The second approach has been to add resources into the primary care setting. The third approach has been to virtually expand primary care through information technology, facilitated access to case managers or specialists, and improved coordination of care such as patient-centered medical home approaches. A non-primary care approach has been to simply move high-need patients to another setting (e.g. dialysis clinic). These interventions are not mutually exclusive and each provides certain benefits. However, even when combined, best practices interventions often do not achieve their anticipated effectiveness.

We and others have argued that the majority of care for older adults must remain in primary care and that we need practice redesign to support this care. In the early 1990s, we conducted an extensive screening program of 4,000 older adults who were approached during their regularly scheduled primary care appointments. The program was designed to assess the prevalence of cognitive impairment, depressive symptoms, suicidal ideation, and alcohol abuse. Less than 25% of patients with moderate-severe cognitive impairment had dementia recorded as a diagnosis; depression and problem drinking were similarly under-diagnosed. Cognitive impairment measured at baseline was a significant predictor of early mortality even when controlling for comorbid conditions. These early observational studies provided the foundation for later intervention clinical trials in primary care. Building from the clinical epidemiologic studies, we completed a randomized controlled clinical trial of physician-targeted interventions to facilitate compliance with recommended standards of care for late life depression. This early clinical trial focused too heavily on the physician factors and too little on system-level barriers described above. This was an important early lesson for improving quality of care in primary care.

We have subsequently participated in three randomized clinical trials focusing on collaborative care models that incorporate case managers into primary care. The trials focused first on late life depression and Alzheimer’s disease, but we then tested the approach among vulnerable older adults with multiple geriatric conditions. We describe each of these trials briefly because each contributes to our understanding of the promise and pitfalls of case managers in primary care. “Project IMPACT” was a multi-site randomized controlled trial conducted among primary care patients with late life depression. Over two years, 1,800 older adults with major depression or dysthymia were recruited from eight sites across the US. Half of the subjects were randomly assigned to a collaborative stepped care program where a depression case manager worked with the patient’s regular primary care provider to treat depression using antidepressant medications and Problem Solving Treatment in Primary Care. The intervention was specifically designed to coordinate care for depression with the patient’s regular primary care provider. Intervention patients were significantly more likely to receive guideline-level care, to recover from depression, and to report improvement in physical function, health-related quality of life, and satisfaction with care.
Building from lessons learned in Project IMPACT, our research team designed a collaborative care intervention based on current treatment recommendations to improve the recognition and treatment of Alzheimer’s disease in primary care. We screened individuals aged 65 and older attending seven urban and racially diverse primary care practices in Indianapolis. Subjects with Alzheimer’s disease were randomized to collaborative care or augmented usual care. Both study groups completed a counseling visit with dementia case manager who provided education about Alzheimer disease and referral to community resources. Over the following year, intervention patients received ongoing care management in collaboration with the patient’s family caregiver and primary care physician. Intervention patients were more likely to receive cholinesterase inhibitors and antidepressants and were more likely to rate their primary care as very good or excellent. Intervention patients had significantly fewer behavioral problems at 12 months and at 18 months as measured by the neuropsychiatric inventory. Intervention caregivers also reported significant improvements in distress at 12 months and sustained improvement in depression at 18 months.

In a recently completed clinical trial, we significantly expanded the primary care reach and scope of case managers into the home of vulnerable older adults. The Geriatric Resources for Assessment and Care of Elders (GRACE) intervention was specifically developed to meet the complex care needs of low-income seniors. Intervention patients received two years of home-based care management by a nurse practitioner and a social worker who collaborated with the primary care physician and a geriatrics interdisciplinary team and were guided by 12 care protocols for common geriatric conditions. This was a randomized controlled clinical trial of 951 low income adults aged 65 or older. Integrated and home-based geriatrics care management for low-income vulnerable elders resulted in improved quality of care and health-related quality of life.

Implementing Case Management for Alzheimer’s Disease in Primary Care

Lessons learned from these prior trials can be used to address the following questions:

1. What are the goal of case management for Alzheimer’s disease in primary care and what activities constitute case management?

2. What are the primary system-level considerations in implementing case management?

3. What are the qualities of the effective case managers? And

4. Are there specificities of Alzheimer disease with regards to case management process?
1. What are the goals of case management for Alzheimer’s disease in primary care and what activities constitute case management.

The goals of case management are to improve the quality of life for older adults with Alzheimer’s disease and their family caregivers. Given that Alzheimer’s disease is a condition that progressively worsens until death, the quality of palliative care and end-of-life care must also be a goal of effective case management. Because health care resources are limited, an additional goal of case management is to maximize the efficient use of health care resources. The table at right is a description of the idealized dementia collaborative care program. Case managers may help deliver all or some of the components of this care program. Looking more closely at the daily activities of case management, one key responsibility is facilitating communication between mental health care, primary care, specialty providers, community service agencies, families, and the patient. This is an active communication role that places accountability on the case manager to “get the right care to the right patient at the right time”. This accountability requires that the case manager have the ability to monitor the longitudinal outcomes of care and respond to care needs through access to the various interventions and resources listed in the Table. Notably, the care manager is not responsible for actually delivering all of the components in the Table. A case manager is a member of a team and a facilitator of a team approach to care. In the context of the care of older adults with Alzheimer’s disease, this team includes at minimum: the patient, the patient’s family, and the primary care physician. However, for most patients the team will also include additional members such as social work, nursing, other allied health professionals, specialist providers (e.g. geriatric medicine, geriatric psychiatry, neurology), and staff from community service agencies. The members and activities of the team are tailored to the individual patient and are expected to remain dynamic over the course of the illness. As the patient’s and family caregiver’s needs change, so will the components of case management.

There are three other key activities of the case manager that are closely related to facilitating communication but may merit special mention: education, navigation, and cheerleading. Education may range from specific, face-to-face, psycho-educational interventions to non-specific provision of written materials or telephone-based instructions.

Characteristics of Ideal Dementia Care Program

1. A feasible dementia identification and diagnosis process including a reliable tool for periodic needs assessment and evaluation of therapy.
2. Pharmacological and psychosocial interventions that prevent or reduce the family caregiver’s psychological and physical burden.
3. Self-management tools to enhance the patient and the caregiver skills in managing dementia disability and navigating the health care system.
4. Pharmacological interventions for care-recipients that target the cognitive, functional, and behavioral and psychological symptoms of dementia such as:
   a. Enhancement of the patient’s cholinergic system via prescribing cholinesterase inhibitors and decreasing exposure to medication with anticholinergic activities.
   b. Improvement in medication adherence.
   c. Reduction in cerebrovascular risk factors such as hypertension, diabetes, and hyperlipidemia.
   d. Prevention and management of delirium, depression, and psychosis superimposed on dementia.
5. Case management and coordination with community resources including adult day care, respite care, and support groups.
6. Modification of the patient’s physical home environment to accommodate dementia disability.
7. An increased focus on palliative care needs as the illness progresses, including advance care planning, attentive management of pain and other symptoms, avoidance of burdensome and undesired medical treatments, and eventual discussion of referral to hospice.
Navigation refers to assistance with moving through and exploiting the available medical and social resources. Cheerleading refers primarily to providing positive reinforcement to the family caregiver and simple acknowledgement of the burdens of that role.

2. **What are the primary system-level considerations in implementing case management?**

Perhaps the most important consideration in successfully implementing case management programs is the understanding that local implementation must be adapted to the local health care environment. The program must be tailored to the individual practice and the design and implementation details must reflect the active participation of the end-users. Prior implementation efforts have often viewed health care systems as machine-like structures with replaceable parts. These machine-like structures are believed to exhibit behaviors that can be predicted based on past performance. For example, this view assumes that functions are carried out by replaceable employees; and that financial incentives, regulatory policies, and best practice knowledge will improve performance. Prior research shows that such approaches often fail due to the local characteristics of patients, employees, resources, and competing demands. The “Reflective Adaptive Process” has been proposed as an alternative approach to introduce acceptable, locally matched, and effective change in a health care system. Reflective adaptive process facilitates the development of local strategies, not prescribed protocols, for quality improvement changes that are built on explicit opportunities for learning, reflection, and adaptation. In our own implementation efforts, we have found that viewing health care systems and individual primary care practices as complex adaptive systems helps us appropriately engage both the leadership and the end-user in the design of the case management program. Because of these considerations, the design of case management programs will appropriately vary and each local implementation effort must therefore take responsibility for assessing local outcomes and adjusting the program as needed. Finally, even within a single health care system or a single primary care practice, one will find important variations among primary care physicians in their attitudes, capabilities, and working styles relative to case management. Adapting to these individual idiosyncrasies can be as important to the program’s success as the adaptation to the local health system.

In the three collaborative care models we tested, case managers had access to a web-based decision-support system that included care protocols, data and reminders about patient contacts, and outcome tracking software. The next generations of this software increasingly provide proactive decision-support based on data about the patient’s current symptoms and treatment. This software also allowed other members of the team to provide oversight on the case manager’s effectiveness from a patient or population perspective. Next generations of this software increasingly capture data on costs and health care utilization to provide evidence of the case manager’s effectiveness from a resource perspective.

3. **What are the qualities of the effective case managers?**

Borrowing from the Dr. Francis Peabody adage: a case manager must be capable of “caring for the patient”. This is probably the only universally required quality of any care provider. Due to their important role in facilitating teamwork and communication with a wide variety of professional and lay team members, excellent interpersonal skills are also valuable. Case managers who are wonderful and caring professionals in a one-on-one setting with a patient are not always capable of effective team leadership or working among the variations in
personality and work styles in primary care. The relative importance of other qualities of the care manager including characteristics such as expertise, specific skill sets, and productivity will vary based on the local adaption of the care management program as described above. Care managers often have a nursing background but social workers, psychologists, and others have also served effectively in this role. In our own programs we have often used advanced practice nurses or coupled advanced practice nurses with social workers. \(^{48}\) Advanced practice nurses have greater training in diagnosis and treatment and, in the United States, have prescriptive authority in addition to their important core nursing expertise. These professionals command higher wages and therefore one must weigh the pros and cons of productivity versus costs as well as availability and local acceptance of such professionals.

Many factors influence the productivity of a care manager. In the collaborative care model we tested among primary care patients with Alzheimer’s disease, the case load of the advanced practice nursing was estimated to be 75 patients per year. The mean number of patient contacts over the year was about 14 with about half of the contacts face-to-face in the primary care clinic. The advanced practice nurse also participated in group support sessions. This advanced practice nurse had considerable information technology and specialty provider support in addition to a strong working relationship with the primary care physicians. However, in the context of the clinical trial, we also added research-specific activities to the case manager’s role which would not necessarily be required in clinical practice. The patient panel of 75 patients in the Alzheimer’s disease study can be contrasted with a panel of 125 patients in our case management study of low-income elders. In that model, the case managers included both an advanced practice nurse and a social worker. This model targeted a much broader group of geriatric syndromes and the patient contacts took place in the home rather than the clinic. Patients received on average about 20 contacts in that study with one-third of the contacts face-to-face; about two-thirds of contacts were with the social worker. \(^{48}\) In summary, productivity will vary based on the patients and conditions targeted, the resources available to the case manager, the sites of care, and the number of patient contacts required to improve outcomes. In the many scenarios one might contemplate to improve efficiency, one must also consider whether these approaches will decrease effectiveness.

Although it is self-evidence that case managers would require training in the specific content of protocols, treatments, and other dementia care options, these case managers also need training to understand the primary care environment. As described in the first section of this paper, primary care is a time-, resource-, and space-constrained environment. Primary care physicians and staff who adjudge that the case manager is not acculturated to this environment will often dismiss the potential of the entire program. In addition to patient contacts, case managers will also have multiple primary care physician contacts. These will nearly always be unscheduled interactions that must take place within the flow of the provider’s other duties. Physicians are trained to provide a brief, one to three minute summary of the key issues relevant at a particular time in the course of care of a complex patient. \(^{60}\) Finding strategic openings for these brief choreographed interactions provides credibility for the case manager’s actual clinical recommendations. Case managers must also learn and respect the roles of other staff in the primary care clinic as part of the acculturation process. Our experience has been that primary care physicians and staff greatly appreciate the help of the case manager if attention is paid to these issues. We generally recommend that case managers assume the demeanor of a guest or visitor until a stronger relationship is developed.

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4. Are there specificities of Alzheimer disease with regards to case management process?

Viewed as a chronic condition, Alzheimer’s disease care models share many of the characteristics recommended in the more general chronic care model. These models often include self-management support, information systems, system redesign, decision support, and activation of community resources. From the case management perspective, there is also much in common among chronic conditions including care coordination, education, medication management, and lifestyle interventions, among others. In contrast, case management for Alzheimer’s disease arguably requires greater attention to goals of care given the limited knowledge available to help judge the risk and benefits of both routine and more invasive treatments and the limited ability of patients to participate in this decision-making. In addition, case management for Alzheimer’s disease nearly always means case management for the patient and a family caregiver or multiple family caregivers. Case management for Alzheimer’s disease also may be unique in terms of the range, instability, variability, and limited treatment options for behavioral and psychiatric disturbances. For many people, such symptoms are more misunderstood and distressing than physical symptoms and this increases the educational and support demands on the case manager.

Conclusions

This report describes the fundamental role of the primary care setting in providing care for older adults with Alzheimer’s disease. The characteristics of primary care afford both opportunities and barriers to improving care for these patients and their caregivers. We describe recent clinical trials of collaborative care conducted at Indiana University that utilize case managers as a mechanism to improve quality. Finally, we explore lessons learned from these trials that may be important to the implementation of these models in other clinical settings. Many questions remain unanswered regarding best practices for facilitating the widespread adoption of these models of care and for discovering even more effective or efficient models of care. Chief among these questions is how nations could take the production and training of these professionals to the scale necessary to meet the demand. We can expect that new medications or other treatments may provide some relief from the enormous care needs for this growing population of patients. Prudence would suggest that we also continue to anticipate the need for new systems of care for those patients who are not spared from the progressive functional decline due to Alzheimer’s disease.

Our research team is pursuing several lines of inquiry that build from our past work and the work of others. First, space limitations in primary care present important barriers to intensifying the content of care provided by case managers in this setting. We need to consider whether some patients at some level of disability would be better served through home visits or in clinical centers specifically designed for this role. Evidence suggests that even with the provision of an ideal dementia care program, Alzheimer’s disease still results in progressive functional decline. We need to continue to test interventions that more specifically target this functional decline, such as occupational therapy and exercise. Third, patients want to remain in their home and better caregiver training, home-based technologies, and coordination with local community resources offer the possibility of delaying or preventing institutionalization. Each of these lines of inquiry requires continued work to improve the capacity and quality of care in primary care because this setting will likely remain the hub of care.
Case Management for Alzheimer’s Disease in Primary Care

Christopher M. CALLAHAN, MD

- Effectiveness demonstrated in clinical trials
- Alternative to drug therapy
- Utilizes caregiver workforce

**OPPORTUNITIES**
- Engage primary care to reduce cynicism
- Engage community services
- Develops teams that can also attend to comorbid conditions

**WEAKNESSES**
- Cost
- Initial investment in infrastructure
- Effectiveness does not approach disease modification

**THREATS**
- Other important chronic conditions compete for time, money, and interest
- Family caregivers will become less available
- Families expect more
References


Yves COUTURIER, Ph.D., is professor at the department of social work, University of Sherbrooke, Canada. He is a member of the Research center on aging. As Canada Research Chair in Professional Practices in Integrating Gerontology Services, Dr. Yves Couturier is studying the way in which health and social services professionals in Canada have implemented these promising models in their day-to-day activities and in their larger institutional practices. By comparing service integration practices in various clinical settings across many developed countries, Couturier’s work will continue to offer current Canadian gerontological practices new and sustainable avenues for development and service integration. Couturier’s detailed results will make it possible to adapt the new service organization models to professional practices, increase Canadian expertise in this field and help put in place new principles for integrated service organization in Canada.
Services’ integration becomes a true innovation once it is perpetuated in professional practices.

Yves COUTURIER, Ph.D.

Canada Research Chair on the professional practices of gerontological services integration
Department of social services, University of Sherbrooke
Research center on aging

1. A TWO FOLD CONTEXTUALIZATION

1.1 A reflexion anchored in the work of the Canadian Chair of research on the professional practices of gerontological services integration

The prolongation of life expectancy, the length of life with feeble autonomy and the increase of the prevalence of health and social care problems that are related to ageing call for an important revision of the organization of care for frail elderly people. The organization of services must evolve from a hospital-centered model dedicated to acute care to a home-centered model devoted to complex chronic care (Hébert et al., 2003). This realignment towards home care provokes a multiplication of care delivery normative systems (public, private or mixed) that constitute fragmentation forces. Fragmentation may be compensated by socio-technological services’ integration devices. In Canada, this type of solution is at the heart of the important reforms of the health and social care system, notably for complex clinical problems (MSSS, 2004) that arise from age-related and mental health issues. The Canada research Chair on the professional practices of gerontological services integration has for objective to foster the appropriation by professionals of the conceptual models, tools and methods related to gerontological services’ integration.

According to Kodner and Kyriacou, integration is defined as “a discrete set of techniques and organisational models designed to create connectivity, alignment and collaboration within and between the cure and care sectors at the funding, administrative and/or provider levels” (2000, published on IJIC). An improved continuity of services for users, which is a fundamental component of recent conceptual models of quality, is expected from the establishment of integration (OMS, 2000; Kröger et al., 2007). Hence, integration can be empirically conceived as a technical device (information, monitoring system, etc.) clinically carried out by professionals, notably by case managers, responsible for evaluating needs and planning and coordinating care. From the users viewpoint, integration improves the efficiency of services, prevents redundancies and continuity breaches, improves user satisfaction and diminishes the family caregivers’ sentiment of being burdened (Hébert et al., 2003)
While considerable conceptual achievements have been reached (ex: Leutz, 1999) and knowledge pertaining to the efficiency of integration continues to accumulate, the role of professionals in the local appropriation of this innovation remains, mostly, misunderstood, and represents the primary aim of the next generation of researchers working in the field (Kodner, 2008). The general objective of the Chair is to understand the conditions and processes that modulate the appropriation of the services’ integration models by professionals.

1.2. Conceiving the socio-technical integration devices as an innovation that finds its finality in professional practices

In the health and social care field, the conception and the implementation of an innovation has as its ultimate function the improvement of services’ quality through the durable transformation of professional practices. For complex innovations, the linear diffusion models seem inadequate to grasp the true movement of their diffusion, from their invention to their routinization in effective practice (Rogers, 2003). In their important synthesis, Greenhalgh and colleagues (2004) conclude their meta-analysis by calling for the development of an analytic framework of an innovation’s appropriation process. Moreover, the scientific literature pertaining to innovation (Greenhalgh and colleagues, 2004; Fullan, 2001) shows that one of the most important determinants of an innovation’s routinization in professional practice is its users’ capacity to adapt it (Barry et al., 2005).

To ensure an innovation’s implementation, its adopters must possess the capacity to translate it into their professional reality, namely to find the best way to adapt it to their local conditions without compromising its integrity in terms of its structural principles (Jané-Llopis & Barry, 2005). This capacity must be encouraged by a supportive implementation infrastructure put in place by its promoters. Hence, the innovation’s diffusion’s process is characterized by an adaptive, or reflexive, rapport between the offer space, that conceives and supports the innovation’s diffusion, and the usage space, that performs it in a particular context. This account details, in our view, one of the main conclusions of Greenhalgh and colleagues’ (2004) review, stating that research pertaining to the diffusion of innovations must focus on the implementation process of innovations rather than on the well documented area of contingency factors. Analyzing the rapport between the offer space and the usage space allows conceiving the professionals’ adaptation of the innovation as the central element of the process. The rapport between the offer and the usage spaces of the innovation can be analyzed as a reflexive process constituted of the following steps:

1) Diagnosis of the prior situation, notably considering the effective coordination practices, the real-life working conditions and the various actors’ expectations in regards to the innovation.

2) Conceptualization adapted to the innovation’s context, in the present case, to the conceptual integrative model’s context.

3) Identification of the innovation’s core tenets, without which the innovation would lose its meaning.

4) Analysis of the innovation’s translation and of its real-life adaptation by the concerned actors during the primo-implementation phase.
5) Modification of the working conditions that hinder the expected appropriation of the innovation and the readjustment of the model during a second phase or modification of the working conditions that hinder the appropriation.

6) Evaluation of the implementation’s success. The implementation will be successful if it meets the following criteria:
   
   a. It respects the core tenets of the innovation.
   b. Favor a significant local adaptation of the innovation by its professionals and users.
   c. It was routinized in transformed professional and institutional practices.

7) Identification of the modulators and adaptation strategies and their transfer towards other contexts.

2. Eight research questions to better conceive the services’ integration professional practices, notably case management

Our work aims to better understand the services’ integration conceptual model's, tools and methods appropriation by professionals in various contexts. These prior research initiatives particularly allowed us to identify a series of issues related to case management.

2.1 How to conceive the difference between ordinary coordination and dedicated coordination?

Services’ integration materializes itself through evaluation, planning and coordination professional practices (Couturier et al., 2007). The conceptual models of integration particularly concern coordination considered as a professional practice aiming to overcome professional and organizational frontiers. It presents itself as “the act of managing interdependencies between activities” (Malone & Crowston, 1991, p. 12). Hence, coordination cannot be reduced to a simple protocolarized approach constrained by technical devices (ex: inter-establishment automated request system) since it comprises as much formal as informal dimensions (Couturier et al., 2007b). If traditional research on services’ integration were efficient at describing the formal dimensions of coordination, its informal facet was the object of much less studies.

One of the main difficulties met during the implementation of a case management device concerns the added-value, as perceived by the professional partners of the case manager, of a case per case management dedicated to coordination, as every actor perceives that an important share of their work to already be to coordinate themselves with others. Written very explicitly, the receptiveness to case management is frequently weak considering that the added-value of a dedicated coordination is altered by the widespread perception that each and every actor already coordinates themselves. If it’s true that all professional actors have the function to coordinate themselves, how then to conceive and promote the added-value of an actor dedicated to this task? How to ensure that this particular form of coordination holds a true added-value for the case manager’s partners in contrast with their regular coordination practices? What distinguishes the ordinary coordination from the more systematized coordination carried out by case management?
To answer this type of question, we must study the effective professional practices of the professionals that are dedicated to integration (case managers, patient navigators or other coordinators) in order to document the professional and contextual modulators of practitioners’ appropriation of conceptual models of integration (Couturier et al., 2010). More specifically, it is important to study the practices that emanate of the three central functions of these trades: evaluating, planning and coordinating according to the disciplinary origins of the practitioners (ex: social work, nursing and paramedical professionals), according to the fields of application (ex: gerontology, childhood difficulties, mental health) or according to the preferred conceptual models of integration.

2.2 How does the interaction between the clinical tools and the case managers inflect dedicated coordination?

Passed studies on integration essentially examined three questions: 1) What is the most adequate organization model to realize integration? 2) How to study services’ integration rigorously? 3) What are integration’s impacts on the health of the target populations and on the performance of the health and social care system? These studies, essentially set in the field of the organization of services, apprehend the object in the light of models. They postulate that a conceptual model of quality will engender roughly transformed professional practices following the model’s expectations. Nonetheless, while it is recognized that the attributes of an innovation, here comprised in the model, are undoubtedly crucial to its successful implementation (Greenhalgh et al., 2004), the necessity to study how these systemic transformations are routinized through the alteration of the professional activity of practitioners is just as important.

It is thus necessary to be able to identify the factors that improve the potential of success of such a local adaptation by the practitioners, notably by accomplishing intersectoral comparisons and by granting particular attention to the gaps between integration conceptions and practices. To do so, it is essential to study what usage (expected or not) the professionals dedicated to integration grant to the three central technical components of services’ integration (Hébert et al., 2003): 1) the planning tools, 2) the evaluation tools and 3) the informational systems. What is the gap between the effective usage of these tools and their effective usages? How do the professionals adapt them to their contexts? How do they compensate for their eventual deficiencies or perverse effects? How is the inter-subjective dimension taken into account in their usage?

2.3 How to conceive dedicated coordination differently than through a more or less explicitly epidemiological paradigm?

The leading conceptual models of services’ integration arise mainly from studies with an epistemological basis and postulate that an efficient needs’ assessment, from which would derivate an appropriate services’ orientation, would allow to increase the efficiency of services. If this postulate is without a doubt accurate, in principle, it collides nevertheless with implementation difficulties. Epidemiology is a discipline that has the tendency to derealize its objects using the principle of all things being equal… However, empirically, this abstract principle that mathematizes reality encounters many resistances. It is thus important to think new action and research logics, in fact to think other integrative forces, setting aside epidemiological logic, to reinforce the integrative capacity of a system. We can think of strategies to animate the social link in the life of the localities that involve professional
competencies of coordination, for example social animation. It is also important to develop a global strategy of services’ integration based upon various action logics since each national context is entrenched in a very particular services’ development history. Hence, a Beveridgian system will not have the same needs in terms of integration than a Biskmarckian or liberal system. Moreover, a context, such as France, where territorial stakes are important can require other integration logics.

2.4 The tension between prevention and treatment of extreme cases or how to conceive clinical complexity

Case management, as a human services’ integration device, is frequently questioned in regards to its added-value in contrast with usual coordination practices. One of the most frequently cited elements of response to justify it is that the clinical complexity of cases should be the object of a case management. The fuzziness of the definition of what constitutes a complex case can provoke a tension between the overall finality of an integration that allows, in a preventive perspective, to avoid or delay autonomy loss, and a case management that would be conceived as a extreme intervention modality only called upon by the most complex cases, combining co-morbidity, social isolation, social problems, refusal of treatment, professional exhaustion, absence of family caregiver and even mental health problems. In fact, this poses the following central question: should we integrate in order to act preventively or create an integrative device which’s primary finality is to compensate the faults of the system for exceptional cases? This tension reformulates the question regarding the integrative aspiration pursued by integration. In our view, we must think the conceptual link between prevention and integration as concerning the operational definition that will be given to clinical complexity as the inclusion criteria to case management. The case manager must have a discreional margin to exercise his clinical judgment, but what knowledge and competences does he mobilize in this judgment? What are the initial and continuous training required to this clinical judgment?

2.5 What is the contribution of family caregivers to coordination and his articulation to the case manager and first line medical doctor?

Case management is the human component of a socio-technical device which aims to integrate services. It can be distinguished from other forms of coordination (ex: between two home care nurses) by its dedicated and systematized character. Thus, between ordinary interprofessional coordination and the dedicated coordination of case managers can be found three other important sources of dedicated coordination, namely the patient himself, the family caregiver and the first line medical doctor. The interface between the first line medical doctor and the case manager remains a relatively unknown space, even though this coordination is crucial to the functioning of the intervention plan. The contribution of the patient/caregiver dyad is even lesser known. Ethically, this lack of knowledge about this contribution matters. For several case management models, the aim is de facto the conscription of the family caregiver, considered as a resource that can be mobilized to the benefit of the intervention system. While it goes without saying that this objective is not conscious, nor smeared by bad intentions, we must recognize that this mobilization modality comprises important ethical issues. How to overcome its negative effects? How to avoid that the family caregiver be utilized to the sole benefit of the intervention system? And what is his true contribution to coordination? An improved understanding of his contribution would allow avoiding unwanted secondary effects (ex: his exhaustion) and to think a public recognition of this contribution.
2.6 The training of case managers. Must we think the qualification of individuals or the development of a collective competency?

The implementation of services’ integration models is so recent that, to our knowledge, no study specifically paid attention to professional training. Yet, studies of general innovation (Greenhalgh et al., 2004) as well as of services’ integration (Hébert et al., 2003) underline the importance of training for the professionals playing the role of case manager. At the field level, there are debates regarding the professional profile of the case managers (social worker, nurse, other?) and regarding the resources deployment strategies (by multidisciplinary or monodisciplinary teams? Co-active teams or sequenced?). Should we train inexperienced individuals to this particular function or rather offer continuous education to experienced professionals? To answer these questions, at least two paths must be explored; firstly, the path of the a priori construction of a referential of competence in regards to the objectives of the innovation or, secondly, a detailed study of the professional knowledge empirically mobilized in action by the case managers. We think this second path is the more important of the two.

2.7 Should we focus on a single illness such as Alzheimer’s disease (and its related pathologies) or think globally the ensemble of autonomy losses linked to aging.

Unearthing here the old debate between case and disease management, the eventual focalization of case management on Alzheimer’s disease is problematic in reason of the nature of the disease itself, that comprises important functional effects, effects that are more frequently re-experienced if the incapacity is not compensated by the quality of the environment of the patient. Case management is as a result in sync with the most recent health conceptual models, thinking the global character of this object as much as a health issue as a social participation issue for elderly people. Hence, case management is required for cases that are complex, evolving, long-term, and for which home care comprises an undeniable clinical value. Alzheimer’s disease is simultaneously emblematic of this client profile, but, in many cases, only a component of autonomy loss. This is why we judge that the abstract partition of these two clienteles is contradictory to the very idea of integrated care.

2.8 Can we find a more attractive designation to conceive case management?

Our many researches on case management allowed us to observe as much fear as hope about this professional figure. If the majority of actors to which this function is proposed express the hope to see it increase the coherence of interventions pertaining to complex situations, they also express numerous fears concerning it. An important share of these fears is expressed through an almost universal hatred towards the case management designation. Judged too managerial for a practitioner who pictures himself free from institutional contingencies (the autonomous practitioner), and reductive in regards to the user that would be confined by this sole designation to the status of “case”, the case management concept would not sufficiently take into account the complexity of clinical situations. We observed more frequently unsatisfactory reformulation attempts. Therefore, it is possible to sustain that the concept has its value, even in its actual designation. The very idea of management, that is to apply decisions in function of the various alternatives offered by a situation, thus holds in itself the necessity to take into consideration clinical singularity. Certainly, the ideal form of the liberal professionality, totally separated from contingencies, exists in the profession exercising...
case management, but the true trade of the case manager has always been the trade of dealing with, that is to manage in the sense of Ogien (1995). Hence, management consists of composing with rules and principles, with resources and needs, in the light of a fabric of constraints which’s technical components cannot embody efficiently on their own. In the semantic field of intervention, the management we are here referring to searches to tie intimately the world of resources to the world of clinical needs into one professional act, founded on the founding value of professionnality that is equity. If this contains the very true risk of a partial subjugation of the clinical imperatives to the systemic imperatives, the absence of linkage between the two is not without ethical consequence on the users. In fact, the clinical/management bonding can allow influencing the systems’ order in favor of a sensible lecture of needs.

In regards to the case dimension of the designation, we largely prefer this theme to client, patient, pathology or problems, which are its primary lexical adversaries. The concept of case calls upon the clinical and systemic consideration of the incarnation in its environment, and in its subjectivity, of a user socially located, bearer of a problem. The employment of the notion of case in the clinical field is homologic to its employment in the scientific field, where the case study requires the in situ and per se apprehension of a phenomenon. A case management approach leads the clinical actors to concentrate on intervening on the diverse dimensions constituting the case, rather than to act on the mono-professional segment of the situation. Linking the clinical and the systemic by creating the conditions of a global account of what constitutes the case can only happen by the presence of a human mediator between the services-system and the client-system. In a bivalent manner (Couturier, 2006), the case manager has for mandate to pull-back into the clinical act the resources constraints as much as he must, statutorily, inflect the system to the benefit of the user as much as possible. That is what Hébert and colleagues (2003) illustrate by employing the image of the UN peacekeeper. Here, the communicational, meditational and at work negotiation competencies of the social actors, as their capacity to mobilize formal and informal resources, and even their community organization competency, gain value. Studying the effective practices of case management will allow us to better understand how the case managers act as such mediators on complex cases, in complex intervention systems.
Services’ integration becomes a true innovation once it is perpetuated in professional practices.

Yves COUTURIER, Ph.D.

**STRENGTHS**

- Clinical and managerial relevance for a collective way of practice
- Necessity for a dedicated coordinator
- Linkage between clinical and managerial concerns

**WEAKNESSES**

- Difficulties to distinguish ordinary and dedicated coordination
- « Integration » of case managers in a real integrated services device

**OPPORTUNITIES**

- Develops team work
- Recognition of the coordination role of family care givers
- Linkage between community services and institutional services

**THREATS**

- Resistance of social workers, physicians and all natural coordinators
- The over mobilization of family caregivers to complete systematic coordination
- Difficulties to coordinate physicians and case managers
BIBLIOGRAPHY


*Case Management – 8 & 9, March 2010*
Clinical Tools of the Case Management

Chair:

Florence Pasquier, MD, PhD, is professor of Neurology, head of the Resources and Research Memory Center at the Lille University Hospital, France. She runs a network of memory clinics for diagnosis and management of dementia in the North of France. She is member of several international scientific societies and academies including Vas-cog (member of the Executive Committee) and of several national and international research networks including the European Alzheimer’s Disease Consortium. She is co-director, with Didier Leys, of a University research team entitled « Vascular and degenerative cognitive impairment » (EA 2691). Involved in clinical research on cognitive and behavioral disturbances, she collaborates on imaging, epidemiology, and basic research. Her main domains of interest are 1) early diagnosis, and differential diagnosis of dementias (special interest in non-Alzheimer dementia, including vascular dementia, frontotemporal dementia and dementia with Lewy bodies) using a multidisciplinary approach : neurological, neuropsychological, behavioral, and more recently biological (CSF biomarkers, genetics ), especially young onset dementias; 2) links between degenerative and vascular pathologies, and 3) Follow-up and natural history of dementias. She is author or co-author of about 200 articles in scientific peer-review journals, more than 40 didactic articles, 40 book chapters, and 20 collaborative group articles, and editor or co-editor of 5 books.

Dominique Somme is a medical doctor graduated in Internal Medicine in 2000 and Geriatrics in 2001. Currently he is practitioner in a University public hospital, the European Georges Pompidou Hospital in the Geriatrics Department (head of department: Pr. Saint-Jean). He is supervisor of the in hospital geriatrics consultation multidisciplinary team. He is also doctor (PhD) in public health. His researches have been firstly directed toward the organisation of the public hospital system, and notably around the use of intensive care resources by aged people (hospital, emergency room, ICU, cardiac surgery). The ethical and economical aspects of the assessment of the outcomes are central to these works. Secondly he was involved as a counsellor for the ministry of Health in a national study on the respect of the citizenship of seniors in the process of institutionalization. Finally, and more recently his research’s topics are on organization of the system of support and care for the elderly at home. In this last field, he is recognized for his expertise on use of clinical tool for individualized intervention of case manager and on the adaptation and assessment of the PRISMA integrated model of care in the French context. The leading of PRISMA France was honoured by the price of the public manager of the year in 2008, delivered by the Ministry of budget, public accounts and public services. In 2009 he was engaged as an expert for the national pilot team of the fourth measure of the national Alzheimer plan. As a public health researcher expert in the national Alzheimer plan, he work for the general department of health in the Ministry of Health and Sport and closely in link with the National Fund for Solidarity and Autonomy. He is responsible for an university diploma in case University.
CLINICAL TOOLS OF THE CASE MANAGEMENT

Speakers:

• Réjean HEBERT

• Roberto BERNABEI

• Daphne NAHMIASH
Réjean HEBERT obtained his Doctorate of Medicine degree from the Université de Sherbrooke in 1979 and a Quebec speciality degree in Geriatric Medicine in 1987. He has also a Diploma in gerontology from the Université des Sciences sociales, Grenoble (1981) and a Master of Philosophy in Epidemiology from the University of Cambridge (1994). He is currently Dean of the Faculty of Medicine and Health Sciences at the Université de Sherbrooke and Fellow of the Canadian Academy of Health Sciences. He was the founding Director of the Research Centre on Aging in Sherbrooke and the Quebec Research Network on Aging (FRSQ). He was also the founding Scientific Director of the Institute of Aging of the Canadian Institutes of Health Research. He is the Director of PRISMA (Program of Research to Integrate the Services for the Maintenance of Autonomy), a unique consortium of researchers, health care managers and policy makers.
CLINICAL TOOLS OF CASE-MANAGEMENT

Réjean HEBERT, MD MPhil
Faculty of Medicine and Health Sciences, Université de Sherbrooke, Québec

With the collaboration of:
Michel Raîche, MSc, Centre de recherche sur le vieillissement, Sherbrooke
Nicole Dubuc, PhD, Université de Sherbrooke
Dominique Somme, MD PhD, Hôpital Européen Georges Pompidou

Dealing with Alzheimer’s disease, like any other chronic diseases, needs to adopt a functional paradigm in assessing the needs of patients and the caregivers as well as designing the health care and social services system. Such functional paradigm focuses on the consequences of the disease in terms of disabilities and handicaps. I personally prefer to refer to the first WHO Classification of Impairment, Disability and Handicap based on the model developed by Philip Wood. The notion of handicap in this model is important for clinical and managerial purposes, since it refers to the way the disabilities are compensated or not by adequate resources (social, architectural, etc.).

The case-management process must be embedded within an integrated service delivery system (ISDS) to be effective. Many studies have demonstrated that an isolated case-management process is not sufficient to produce an improvement in the efficacy of a health care system. Otherwise, integrated service delivery systems including case-management have demonstrated efficacy. Large studies carried out in Québec over the last ten years have tested two different models of ISDS: the SIPA (Services intégrés pour personne âgées) project was based on a full-integration model according to the Leutz classification, whereas the PRISMA (Programme de recherche sur l’intégration des services de maintien de l’autonomie) project tested a coordination-type model. Both confirmed that an ISDS has beneficial effects on the patients as well as on the health care system. Both models included case-managers (CM), as well as standardized tools for triaging, assessing, and managing the patients. The PRISMA project included also a Computerized Clinical Chart, accessible by all services and professionals (including CM). This CCT was found very effective in fostering the integration of services and improving the efficacy of CM.

After having briefly described the PRISMA model, we will focus on the four types of instruments used by the CM for: 1) triaging the relevant patients to the ISDS; 2) assessing the basic needs of patients; 3) managing the system; and 4) planning services by producing an Individualized Service Plan. Many instruments could be appropriate for these purposes, but
we will focus on those that were included in the PRISMA experiment and demonstrated their utility in this project.

DESCRIPTION OF PRISMA MODEL

The PRISMA model\(^4\) comprises six components: 1) co-ordination between decision-makers and managers at the regional and local levels, 2) single entry point, 3) case management, 4) individualized service plans, 5) single assessment instrument coupled with case-mix management system, and 6) computerized clinical chart.

**Co-ordination** between institutions is at the core of the PRISMA model. Co-ordination must be established at every level of the organizations. First, at the strategic level (governance), by creating a Joint Governing Board (JGB) of all health care and social services organizations and community agencies (public, private and voluntary) on which the decision-makers agree on policies and orientations and what resources to allocate to the integrated system. Second, at the tactical level (management), a service co-ordination committee, mandated by the JGB and comprising public and community service representatives together with older people, monitors the service co-ordination mechanism and facilitates adaptation of the service continuum. Finally, at the operational level (clinical), a multidisciplinary team of practitioners around the case manager evaluates patient needs and delivers the required care and services.

The **single entry point** is the mechanism for accessing the services of all the health care institutions and community organizations in the area for a frail senior with complex needs. It serves as a unique portal that older people, family caregivers and professionals can access by telephone or written referral. A link is established with the Health Info Line available to the general public in Quebec 7 days a week, 24 hours a day. Callers are screened using a brief 7-item questionnaire (PRISMA-7) that evidences good levels of sensitivity and specificity in identifying significantly disabled older people. A detailed assessment of disabilities is then undertaken for those screened positive; individuals deemed eligible for ISD are then referred to a case manager. The eligibility criteria are: to be over 65 years old, to present significant disabilities (as defined by a SMAF score over 15 or an Iso-SMAF Profile over 4), and to need more than three different services.

The **Case Manager** (CM) model included in PRISMA draws directly from those described as Clinical CM (Scarlach et al.\(^5\)), Neighborhood Team (Eggert et al.\(^6\)), or Basic CM (Phillips et al.\(^7\)). The CM is responsible for conducting a thorough assessment of the patient’s needs, planning the required services, arranging patient admission to these services, organizing and coordinating support, directing the multidisciplinary team of practitioners involved in the case, advocating, monitoring and re-assessing the patient. The CM is legitimate for work in all institutions and services. The CM can be a nurse, a social worker or another health professional and should be specifically trained. An ideal caseload is around 40 patients per CM. Figure 1 summarizes the flow of patients through the coordinated PRISMA model.
The Individualized Service Plan (ISP) results from the patient’s overall assessment and summarizes the prescribed services and target objectives. The ISP is led by the CM and established at a meeting of the multidisciplinary team including all the main practitioners involved in caring for the older person. The ISP should be validated with the patient and the informal caregivers, so that they are empowered in the decision-making process.

The single assessment instrument allows for evaluating the needs of clients in all organizations and by all the professionals working either in home care organizations or in hospitals and institutions. The instrument implemented in the PRISMA model is the SMAF (French acronym for Functional Autonomy Measurement System) and its management part, the Iso-SMAF Profiles.

Finally, the PRISMA model includes a Computerized Clinical Chart (CCC) to facilitate communication between organizations and professionals. The SIGG (French acronym for Geronto-Geriatric Information System) was developed and implemented in a pilot project in the Bois Francs area (Victoriaville, Quebec, Canada)\textsuperscript{8}. This shareable clinical chart uses the Quebec Ministry of Health and Social Services Internet network and was developed on a Lotus Notes platform.

The following Table reports the degree of implementation of each of these six elements during the PRISMA experiments.
Degree of implementation of the PRISMA model in the three experimental regions

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<td><strong>69.9</strong></td>
<td><strong>76.4</strong></td>
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</table>
TRIAGE INSTRUMENT: The PRISMA-7

The PRISMA-7 case-finding tool had been developed to identify older adults with moderate to severe disability, who could benefit from integrated services. The PRISMA-7 was developed from a re-analysis of a longitudinal study on functional decline of community-dwelling older people. From a random sample drawn from the electoral list of the Sherbrooke urban area, 594 community-dwelling subjects over 75 years old were selected, returned a postal questionnaire and were then evaluated at home. The postal questionnaire included 23 questions (answered by yes/no) developed according to a literature review on risk factors for functional decline. The functional autonomy was evaluated at home with the SMAF (Functional Autonomy Measurement System). The definition of moderate to severe disability was a SMAF score ≥ 15 out of 87. From the 23 questions, seven were identified as the best descriptors of a result ≥ 15 on the SMAF scale (figure 2). A cut-off score of three or more positive answers yields a sensitivity of 78.3% and a specificity of 74.7%, identifying 35.5% of the aged population as positive. A cut-off score of four or more positive answers results in a 60.9% sensitivity and a 91% specificity (19% labeled positive).

Since PRISMA-7 consists of seven yes/no questions, it is comparatively simple to use. It is necessary merely to follow a few instructions, the main one being that the elder’s answers must be considered correct. A user guide has been developed and published in the form of a book chapter.

The Eastern Townships region in Québec, Canada, implemented different approaches to identify the disabled older persons. The tool has been used progressively in different settings and at different times, including the single entry point for accessing services for older people in Sherbrooke. Implementation began in emergency departments at the university hospital. At the start, the case-finding was done on a proportion of 10% to 20% of the clients. This rose to between 50% and 60%, depending on the facility. Surgery preparatory clinics then started using the tool. The annual influenza vaccination campaign provides a good opportunity to perform quasi-systematic case-finding. Using PRISMA-7 in all these settings could be described as a mix between an opportunistic (single entry, emergency, surgery preparatory clinics) and systematic (influenza annual vaccination) approach. The persons identified by the tool should then be referred for disability assessment.
### Figure 2: The Seven PRISMA-7 Questions

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Are you more than 85 years old?</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td>2. Male?</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td>3. In general, do you have any health problems that require you to</td>
<td>Yes</td>
</tr>
<tr>
<td>limit your activities?</td>
<td>No</td>
</tr>
<tr>
<td>4. In general, do you have any health problems that require you to</td>
<td>Yes</td>
</tr>
<tr>
<td>stay at home?</td>
<td>No</td>
</tr>
<tr>
<td>5. Do you need someone to help you on a regular basis?</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td>6. In case of need, can you count on someone close to you?</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td>7. Do you regularly use a cane, a walker or a wheelchair to move about?</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of Yes and No answers</th>
<th>___</th>
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</table>

98
ASSESSMENT INSTRUMENT: The SMAF

The SMAF (Système de mesure de l’autonomie fonctionnelle) is a 29-item scale developed according to the WHO classification of disabilities. It measures functional ability in five areas: activities of daily living (ADL) [7 items], mobility [6 items], communication [3 items], mental functions [5 items] and instrumental activities of daily living (IADL) [8 items]. For each item, the disability is scored on a 5-point scale: 0 (independent), -0.5 (with difficulty), -1 (needs supervision), -2 (needs help), -3 (dependent). The resources available to compensate for the disability are evaluated and a handicap score is deducted. The stability of the resources is also assessed. A disability score (out of -87) can be calculated, together with sub-scores for each dimension. A social sub-scale with six items has been recently developed and validated.

The SMAF must be administered by a health professional that scores the subject after obtaining the information either by questioning the subject and proxies, or by observing and even testing the subject. The SMAF is available in French and English as well as 12 other languages.

The inter-rater reliability of the SMAF was first verified in a study of 150 community-dwelling subjects who were evaluated twice within 24 hours by two different raters. The ten pairs of raters were selected from two different professional groups (nurses and social workers) practicing in community or institution settings. The objective was to check if the rater’s profession or usual practice environment influenced the reliability of the rating. The raters had attended a three-hour information session on the instrument. The subjects were randomly drawn from lists of home support services clients and people waiting for a place in a residential facility. The results showed that the raters agreed on the score in 75% of the cases and that the scale presented a mean weighted kappa coefficient of 0.75. These reliability indicators did not vary according to the raters’ profession or practice environment.

When the instrument was revised in 1993 and the -0.5 level was added to most of the items, the reliability of the scale was tested again. This time, the stability of the overall score was also examined with a view to using the tool for epidemiological or evaluative research purposes. For this study, 90 subjects were randomly recruited from nine different living environments ranging from community-dwelling to long-term care institutions. Half the subjects were evaluated twice by the same nurse at a two-week interval (test-retest reliability) while the other half were evaluated by two different nurses over the same time interval (inter-rater reliability). The agreement percentages and weighted kappa for the inter-rater reliability were comparable to those measured in the first study. For the total score, the intra-class correlation coefficient (ICC) was estimated to be 0.95 (95% confidence interval: 0.90 to 0.97) for test-retest reliability and 0.96 (95% confidence interval: 0.93 to 0.98) for inter-rater reliability.

This study also determined the minimal metrically detectable difference on the total SMAF score. This is the random error produced by the reliability limits of the instrument. This difference is 5 points and represents the lower limit of a clinically significant difference between two groups of subjects or between the same group of subjects at two different times. This 5-point limit has been used to determine a significant loss of autonomy in
epidemiological studies and in effectiveness studies where the loss of functional autonomy is the outcome variable.

The content validity of the SMAF was first established by its development based on a recognized conceptual framework and the selection of the items based on the WHO classification of disabilities, and a review of the scales previously published and validated in this field. The validity of the SMAF has also been the subject of several empirical studies. The first study compared the SMAF score obtained with 99 institutionalized subjects with a measure of required nursing care time using the instrument PLAISIR 84 (Planification informatisée des soins infirmiers requis [Computerized planning of required nursing care]). A correlation coefficient of 0.88 (p<0.001) was observed between the two instruments. This study was replicated with a larger sample (1,997 subjects) including subjects living at home and in different types of institutions. In this study, nursing care time was measured using the modified instrument CTMSP (Classification par type en milieux de soins prolongés [Classification by type in long-term care settings]). The correlation coefficient was 0.92 with the SMAF explaining 85% of the variance in the required nursing care time. The regression equation used to predict the nursing care time based on the SMAF score was as follows:

\[
\text{Log (required nursing care time + 1)} = 0.118 + [0.0213 \times \text{SMAF}]
\]

Thus, for a SMAF score of 20, the log (required nursing care time + 1) would be 0.544 for an antilog of 1.723 and required nursing care time of 0.723 hours or 43.4 minutes per day.

The same study also linked the SMAF score to the total cost of the services received by the subjects including care, surveillance, infrastructure (furniture and facilities), operations (meals, maintenance, etc.) and administrative support. With these data, the SMAF can be used in cost-benefit studies because the financial benefits can be calculated from the differences in the observed SMAF scores. This study done with a representative sample of subjects also provided reference data on the distribution of the SMAF scores in the clienteles in these three living environments. The median total SMAF score was 13.5 (semi-interquartile interval: 6.5) at home, 29.0 (7.5) in intermediate resources and 55.0 (13.5) in long-term care institutions. These results confirmed the SMAF’s ability to distinguish between clienteles with different needs, which supports the discriminant construct validity of the instrument.

A study done with 80 subjects admitted to an active rehabilitation unit and in long-term care institutions matched for age, sex and initial SMAF score compared the SMAF to two other disability measures: the Barthel Index and the Functional Independence Measure (FIM). The objective was to document the responsiveness of these three scales by comparing the difference in scores between leaving and being admitted to the active rehabilitation unit in subjects in the active process of functional recovery and that observed over a similar period in subjects whose autonomy was stable. The studied showed that the Guyatt Index, a measure of responsiveness, was 14.5 (95% confidence interval: 9.6 to 19.5) for the SMAF, 13.7 (9.0 to 18.4) for the FIM and 12.8 (8.8 to 16.8) for the Barthel Index. The difference between these indexes was not statistically significant. This study also showed correlation between the SMAF and FIM (r=0.94) and between the SMAF and Barthel Index (r=0.92), which represents concomitant construct validity.

The SMAF is included in the OEMC (Outil d’évaluation multiclientèle) in Québec for assessing all people requiring services either at home or in institutions. A computer program is available.
for completing the SMAF: the eSMAF. A training manual and a training program are also available. The SMAF has been successfully implemented in France (Dordogne) for assessing older and handicapped people in home care services and in institutions. From the SMAF, the AGGIR scale could be completed and a GIR can also be determined.
MANAGEMENT TOOL: The Iso-SMAF Profiles

The Iso-SMAF Profiles is a case-mix classification system developed from the SMAF and based on the needs of people, as opposed to most classification for long-term care that are bases on the utilization of resources. Fourteen Iso-SMAF profiles were generated using cluster analysis techniques in order to define groups that are homogeneous in regard to profile.

Iso-SMAF profiles are characterized from the first to the last profile by an increase in the mean level of disability ranging from 9.4 to 73.8 out of a potential 87. The first three profiles include subjects who show mainly IADL disabilities in the form of difficulty (profile 1), need for supervision (profile 2) and need for help (profile 3). From profiles 4 to 10, there is a progression of disabilities in domestic activities and ADL accompanied, for the most part, by predominant alterations either in mobility functions (profiles 4, 6 and 9) or mental functions (profiles 5, 7, 8 and 10). Profiles 11 and 12 are characterized by mixed alterations in mobility and cognitive functions, and an equivalent level of disability. Even though these profiles present the same levels of disability and the same total amount of nursing care, the elderly exhibit different needs in specific aspects. In fact, in profile 11, the elderly generally present occasional urinary incontinence, maintain bowel function, need help for transfers and to walk; in contrast group 12 are frequently or always incontinent, walk independently but still need guidance, and demonstrate major behavioral problems such as wandering and aggressive behaviors towards themselves or others. Finally, profiles 13 and 14 show the lowest level of autonomy with dependency in all ADL activities. The fourteenth profile includes people who are no longer able to communicate and who show severe cognitive impairment with minor behavioral problems (e.g. complaining). Figure 3 summarizes the profiles.

Each profile is associated with a specific number of hours of nursing care, support and supervision needed, with architectural requirements and with the cost associated with caring these people. The profiles are used to establish the eligibility criteria to the different services and to calculate the required budget of the organizations, based on the disabilities of their patient groups.
Figure 3: The Iso-SMAF Profiles.

Legend
- Autonomous (0)
- Difficulties (0.5)
- Supervision (1)
- Help (2)
- Dependence (3)

1. **Problems in Instrumental Activities of Daily Living Only**
   - Difficulties
   - Supervision
   - Help

2. **Predominant Alterations in Mobility Functions**
   - Autonomous ADL
   - Difficulties ADL
   - Help ADL

3. **Predominant Alterations in Cognitive Functions**
   - Moderate + difficulties ADL
   - Severe + difficulties ADL
   - Severe + supervision mobility
   - Severe + help ADL

4. **Mixed Alterations Mobility + Cognitive**
   - Without incontinence
   - With incontinence

5. **Bedridden and Dependency in ADL**
   - Severe cognitive impairment
   - Very severe cognitive impairment
PLANNING TOOL: The Individualized Service Plan (ISP)

The instruments used by Case Manager to identify relevant clientele or assessing needs are numerous and well validated. On the contrary, the planning task, which appears to be essential since it governs implementation, monitoring, and reassessment, hasn't received the same kind of attention. Yet many authors view the formulation of an individualized service plan as an essential component in integrating services to the elderly with a loss of independence. For some, it represents a case-management quality criteria. As with assessment, the plan is both a set of processes and a product in the form of a written document placed in the person's file. To our knowledge, no planning document has ever been validated scientifically. Consequently, the tools used for planning usually derive from that used for assessment. In Quebec, the definition of individualized service plan used by the Ministère de la Santé et des Services Sociaux refers to the process designed to achieve social integration and to provide an individualized response to the person's needs. It requires that the person or the person's representative attend a meeting targeting cooperation and collaboration. This definition, like others around the world based on major consensual principles, does not, however, explicitly state how the individualized service plan leads to clinical integration and how important developing the individualized service plan document is to integration. This is also observed in the literature: while the individualized service plan is often cited as an important feature of integration, its design, expected content, size, usefulness, and use are not defined.

The PRISMA integration experiment, in which case managers were asked to develop individualized service plans, enabled Dominique Somme and the PRISMA Group to clarify these individualized service plan aspects using qualitative methods. A total of 50 files were analyzed, together with interviews regarding individualized service plan use with all the case managers (n=13).

Delays between starting case management and writing the individualized service plan were long and varied (0-596 days, mean: 117 days). During the interviews, the individualized service plan was described as the "last step", once the active planning phase was over. The reasons for formulating plans were mainly administrative. From a clinical point of view, individualized service plans were used as memorandum, and were not descriptions of services (842 interventions not mentioned in the individualized services plans) or needs (694 active problems not mentioned). Case managers felt uncomfortable with the individualized planification task and expected a tool more adapted to their needs.

Although a majority of the case-managers' files contained an individualized service plan, this tool implementation seems tenuous. Because of the discrepancy between the potential usefulness expected by case managers and actual use, a task force was created by the Quebec Ministry of Health to developing proposals for modifying the instrument. The task force was composed of 17 professionals from a variety of disciplines representing all clienteles across Québec who might benefit from an individualized planning process, as well as a clinician-physician-researcher from France. The group worked with researchers and administrators at different decision-making levels (the Ministry, Regional Board, program managers) and clinicians with individualized planning experience. The members of the task force included physicians (community health specialist, general practitioner and geriatrician),...
managers, case managers, nurses, social workers, a psychologist-educator, and a representative from the Québec office for disabled persons.

The task force proposed a dynamic, concise, user-friendly tool and a clear definition of how it should be used. The Individualized Service Plan list the patient’s needs, with an orientation regarding the action plan for each, and a list of services allocated in response to these needs that work in the defined direction. The tool also contains a section for analyzing variations between the services needed and allocated. The elements of the tool are presented in Figure 4.

The structure of the tool separates the needs assessment from the solutions eventually offered, and thus needs not covered by available services can be identified. Thus, the use of this tool requires case managers to be able to work in a context where they have confidence in their employer in identifying these imbalances between needs and services. This aspect underscores the importance of creating joint strategic and tactical accountability in parallel with the development of case management. The other major change from “traditional” planning tools is the use of written orientations rather than measurable and/or quantifiable objectives with thresholds and delivery timelines, which are a matter of each professional’s judgment, helped if necessary by the interdisciplinary team to which the professional belongs. Identifying refusal of services as a need and a cause of non-delivery also makes it possible to take into account the important work done by case managers, who often work with populations with psycho-behavioral disorders.

This tool was presented to case managers for validation and received an enthusiastic response. The tool needs to be integrated into a computerized clinical tool. Such a computerization is in fact the only way to guarantee that the tool is actually updated on a continuous basis and used by all the partners who may need it via a secure network. Broader dissemination would require a training program in parallel with using the tool. The target of this training program should be very broad, not limited simply to those who may write the document but including all professionals who may be involved in an individualized services plan initiative. It appears that an important condition for implementation is that the managers of services find it useful, through the aggregation of information from individualized services plans developed by case managers, in doing territorial planning based on clients’ needs. There is no scientific research made until now on implementation measure of the new "individualized services plan" and no validation study (but the gold standard is also unavailable). However, Somme et al. previous studies indicate that if a tool is not used, there is reason to question the ergonomics of the tool itself rather than the less-than-perfect practices of professionals.
Figure 4: Structure of the individualized services plan tool proposed by the multidisciplinary multiclientele task force on the planning of services in Québec

<table>
<thead>
<tr>
<th>INDIVIDUALIZED SERVICE PLAN</th>
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<tbody>
<tr>
<td><strong>Information concerning the person or the file</strong></td>
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</tr>
<tr>
<td>• Date individualized services plan was written or modified;</td>
<td></td>
</tr>
<tr>
<td>• Name and position of the writer, to contact if necessary;</td>
<td></td>
</tr>
<tr>
<td>• Date of the most recent “needs assessment”;</td>
<td></td>
</tr>
<tr>
<td>• Projected date of the next needs assessment;</td>
<td></td>
</tr>
<tr>
<td>• Participants in the most recent multidisciplinary meeting;</td>
<td></td>
</tr>
<tr>
<td>• Legal situation or protection plan if applicable;</td>
<td></td>
</tr>
<tr>
<td>• Names and contact information of family caregivers if applicable;</td>
<td></td>
</tr>
<tr>
<td>• Date, participation method and signature of the person or his/her representative, to confirm their participation in the individualized planning process;</td>
<td></td>
</tr>
<tr>
<td>• Other information that may be useful in the planning process.</td>
<td></td>
</tr>
</tbody>
</table>

### Needs

This section is used to plan services based on the person’s aspirations, expectations and life plan, expressed as needs. Priority needs are identified. Needs must be precise and individualized enough for the orientation (the direction to give to actions or services) to be written concisely, usually using just one verb.

*For example:*

**The “transportation” need will be written as “transportation to the day centre”, “transportation by car every day”, etc.**

**If pain is the reason for restricted mobility, “mobility” will be written as “pain during mobility”.**

**The refusal of possible help to meet a need must be clarified: “refusal of help with bathing”, “refusal of psychosocial help”, etc.**

### Services allocated / Contribution of family caregivers

This section is used to coordinate services and monitor the individualized services plan since it contains all the services allocated, with names, contact information, frequency, projected schedule, and duration of the intervention. The following should be included here:

- Public, private and community intersectoral services
- Family caregivers, relatives, significant persons
- Family physician and medical specialist(s)

The expression “as needed” for service frequency should only be used if the need is clearly identified, with an appropriate strategy for identifying this need, if the need is unpredictable and irregular, and if the service can in fact be provided on demand. In all other cases, the frequency should be indicated.

### Orientations

This section indicates the general direction of the actions and supports the consistency and coherence of the actions taken and to be taken. These orientations are shared with the person.

*For example:*

*Compensate for,*

*Assess,*

*Etc.*
**Initiatives and periodic services**

This section is used to monitor the progress of the current initiatives and periodic services, for example, meeting with relatives, appointment with a medical specialist, request for a service that could otherwise be requested by various case workers, submission of an expert assessment report, etc. With details regarding their types, expected date.

**Orientations**

This section also identifies the orientations which each of the allocated services must address.

<table>
<thead>
<tr>
<th>Analysis of unmet needs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Unmet needs</strong></td>
</tr>
<tr>
<td>Aspirations not met and problems not resolved</td>
</tr>
</tbody>
</table>
TO KNOW MORE ABOUT PRISMA:

Web site (in French or English): [http://www.prisma-qc.ca](http://www.prisma-qc.ca)

Two books were published in French and English about the PRISMA experiment:


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Roberto BERNABEI, MD, was born in 1952 and graduated at the Università Cattolica del Sacro Cuore (U.C.S.C.) where he attended the Internal Medicine residency. Professor of Internal Medicine at the U.C.S.C. (1990-) and Director of the Department of Geriatrics and Rehabilitative Medicine of the A. Gemelli University Hospital (2004-), the largest Geriatric department in Italy. One of the largest in Europe. Visiting professor at the Department of Community Health of Brown University School of Medicine (2000-). Executive-vice president of interRAI, a US non-profit corporation of scientists of 27 countries producing standardized assessment instruments for the frail elderly (1992-). Board member of the European Academy for Medicine of Aging (EAMA) (2000-). Member of the special joint commission (Ministry of Health-Ministry of Labour) for the disability in the elderly and related problems (2003-). Member of the Consiglio Superiore di Sanità, the highest consultative organism for the Italian Parliament and Cabinet (2002-2005/2006-2009/2010-2013). President of the Italian Society of Gerontology and Geriatrics (2006-2009). Member of the Geriatric Working Group of the Agenzia Italiana del Farmaco (2009-). Member of the Board of Directors of the Università Cattolica del Sacro Cuore (2010-). His main research interests are in geriatric assessment, models of health services for elderly care, geriatric pharmaco-epidemiology and drugs use. Project leader (2000-2004) of a large European Commission’s grant (FP5) involving 11 EU countries to define the best home care model for the elderly. Project leader (2009-2012) of an other EU grant (FP7) involving 9 countries to define the best nursing home model for the elderly. Author of over 250 papers published in peer reviewed journals, four books, eight book chapters.
Case Management in Alzheimer’s Disease

Roberto BERNABEI

*Department of Gerontology and Geriatrics, Catholic University of Sacred Heart, Rome, Italy*

Improving the ability of healthcare systems to respond to the needs of older people (in particular of those suffering from Alzheimer disease) is among the greatest challenges of our time. Because of the growing number of older people and their high rate of comorbidity, disability and cognitive impairment, there is a great need for preventive and home care programs. Furthermore, evidence shows that community care may achieve better outcomes at lower costs than institutional services and be preferred by older people, often even when they are terminally ill. As a consequence, home care has been among the fastest growing segments of the healthcare industry in the United States and in many European countries.

Comprehensive and appropriate treatment goals and plans (“case management”) that meet all patients’ needs can only be developed as a result of thorough assessment of the patient, the family, and the home environment. The assessment should address the patient’s medical condition, including functional status, cognitive status, other medical conditions, behavioral symptoms, psychotic symptoms, and depression. The assessment should also address the patient’s support system, identify the primary caregiver and the patient’s decision-making capacity.

Despite evidence of their positive outcomes, case management strategies are not sufficiently implemented in Alzheimer disease of older adults. This may be related to the fact
that the responsibility of various health professionals for the “case” management of older people living in the community remains poorly defined. Several studies suggest that a possible solution may be the integration of medical and social services in a continuum of care with case management programs. A study by Williams et al. in 1973 demonstrated an extraordinary benefit and cost saving from a comprehensive evaluation of individuals judged to need long term care placement. More recently, in the US, the Program for All-inclusive Care of the Elderly (PACE) has been hailed as a model of integrated care for elderly persons who are covered by both Medicare and Medicaid, and who are eligible for nursing home care but remain living in the community. This program is based on the integration of services, achieved through consolidated case management by the multidisciplinary team (responsible both for managing cases and for dispensing services). Case manager supports and integrates the activity of general practitioners, performing a comprehensive geriatric assessment and implementing individualized care plans.

A recent study demonstrates that an integrated community care program implemented by an interdisciplinary team including a case manager is associated with an higher rate of use of preventive strategies and lower burden for caregivers. In this experience case managers were trained to perform a comprehensive geriatric assessment and to design and implement individualized care plans. They also determined the services which each person was eligible to receive. In such a model the case manager supports and integrates the activity of general practitioners, representing the gatekeeper to health care services. Therefore, the case manager approach offers a single community ‘setting’ the patients can refer to, regardless of specific needs and diseases. Case managers can help elders to become more compliant with medications and with rehabilitation and/or occupational therapy programs, as well as preventive strategies.

The close collaboration among case managers, community geriatric evaluation units and general practitioners is critical to the success of this approach. As a consequence, caregivers are more satisfied of the health care and assistance received and they seem to suffer less burden for caring activities.
The case management approach has been shown to be a crucial link between the assessment of medical and social services and the allocation of health care resources. A review of case management programs utilized to deliver primary care to elders with Alzheimer disease, heart failure, diabetes, and mixed comorbidities found that most showed improved outcomes compared with controls. Furthermore, a case management approach resulted in less progression of functional decline in persons in the community and reduced permanent nursing home stays compared with controls. Also, results of randomized clinical trials showed that primary care coupled with a case manager approach can prevent hospitalization and institutionalization leading to a reduction in health care expenditures. Based on these findings it can be hypothesized that part of these health benefits may be obtained through a higher use of preventive strategies and lower caregiver burden.

The results of international studies support the idea that case management, when included in a model of home care service, has a positive effect on healthcare outcomes. Many authors demonstrated that an integrated community care program implemented by an interdisciplinary team including a case manager reduced the risk of being institutionalized in a nursing home.

The role of case manager need to be addressed (sometimes called care managers, service coordinators, care coordinators):

- **evaluate problems**, through comprehensive assessment of the elderly physical, social and psychosocial condition using validated assessment tools;
- **identify solutions**, developing a comprehensive care plan which include the services that the elderly requires;
- **arrange services**, assisting the elderly to link up with the services identified in the care plan;
- **follow-up and monitor care**, ongoing follow-up and review of the care plan by case managers to make sure that the elderly needs are taken care of.

The geriatric case manager is a professional, such as a social worker, counselor, nurse, or gerontologist with either social work or nursing background. In our experience nurses are the preferred professionals to become case managers. Community Case
Managers are trained to assess the needs of the elderly and provide support to caregivers. They are well versed with the eldercare services available in the community, and are able to co-ordinate a comprehensive array of services to meet the needs of the elderly (medical and social needs).

Considering the evidence addressed, some features of the best practices may explain the case management positive results:

- **the role of Case Manager** – ability to design care plans and co-ordinate all available services, so assuring integrated care;
- **single entry point** – the community geriatric evaluation unit (or something analogue) represents the only gatekeeper to health services; this provides a unique community-based setting to refer patients, regardless of specific needs;
- **case Manager into a multidisciplinary team** – the close collaboration between case managers, community geriatric evaluation unit and general practitioners is critical to the success of the intervention; this may determine the effectiveness of any community-based programs.
- **new assessment “system” (interRAI-HC)** – second and third geriatric assessment instruments ([www.interrai.org](http://www.interrai.org)) yields better results in terms of physical functioning and costs savings as compared with traditional geriatric assessment.

In conclusion, the evidence shows that the development of cost-effective, integrated systems of care for frail elderly are possible. Despite positive results, none of the experimental models to date have been successfully generalized on a large scale. Further analyses are needed to define the specific groups of older people that such home care programs most effectively target and to confirm the positive effect of case management on clinical outcomes and healthcare costs. Then the incentives will be in place to think about appropriate changes in the healthcare delivery systems of the nations.
Case Management in Alzheimer’s Disease

Roberto BERNABEI

- Indepth validation in English and at least interrater reliability in all languages
- 2-3 revisions in almost 20 years
- Comprehensive assessment health care setting specific
- “intelligent” instruments with a triggering process
- Care planning oriented
- Standardization
- Core items in common for all the instruments
- Case-mix availability
- Short training
- Ongoing contribution in the scientific contents from more than 50 experts in the field

STRENGTHS

- Standardised training
- Length of the forms
- Ten year in advance with respect to the overall culture of the system

WEAKNESSES

OPPORTUNITIES

- Construction of large databases from a scientifically proven instrumentation
- Transformation of a daily clinical work in scientific data
- Scientific data for policy makers, for analysis of outcomes, for politics
- Economic reimbursement case mix driven
- Quality assurance and benchmarking for different services or structures
- Make it possible the continuity of care and to track down the person in need
- Increase of culture and motivation in the exposed personnel
- Continuing education processes are eased

THREATS

- A comprehensive assessment tool produced by “others” frightens
- The software is mandatory and it has costs
- Data produced by the assessments need to be managed and read properly
- Sometimes “the solution” (look at strengths and opportunities sections...) produces antibodies!

Case Management – 8 & 9, March 2010
Daphne NAHMIASH

PRESENT ACTIVITIES
Appointed Member of National Seniors Council
Member of Elder Abuse Team of National Initiatives of Care of the Elderly
Member of the consultation team on Emergency Preparedness of seniors for disasters
Chairperson of NDG Community Committee on Elder Abuse, Montreal, Quebec
Consultant in Gerontology

EDUCATION
1993-97 Doctorate in social service
School of Social Service, Laval University, Quebec
1968-79 Masters in Social Work
McGill University, Montreal
1962-63 Diploma in Social Administration
London School of Economics, London, UK
1959-62 B.A. hon. degree in German and French subsidiary
Bristol University, Bristol, UK

MOST RECENT EMPLOYMENT
April-05-March-07 Consultant – Responsible for the accreditation of the CLSC NDG/MTL-O and Commissioner of Complaints and responsible for the Quality of Services for CSSS Cavendish
2002-March 2005 Director of Professional Services
CLSC NDG/MTL-O, Montreal
1988-present Member of Education Committee of McGill Center for Studies on Aging
Faculty of Medicine McGill University

PAST EMPLOYMENT
1998-2001 Adjoint Professor, Responsible for the Certificate in Gerontology
School of Social Service, Laval University (retired May 31st, 2001)
1988-1997 Honorary Professor
McGill University, Faculties of Medicine and Social Service
McGill University School of Social Work
1988 MSW & Bacc. courses in Social Work
Masters Program: Family Caregiving and Intergenerational Social Work
Supervision of Masters students and research reports.
1989-90 President of Masters in Social Work Committee & Research Committee in School of Social Work
1992-93 General courses for both Bacc. & Masters students
1993- Member of Centre for Applied Family Studies
Faculty of Medecine, McGill University
1996- President of Education Committee, Centre for Studies in Aging
1988-96 Member of diverse committees, Centre for Studies in Aging
Department of Occupational Therapy and Physiotherapy, McGill University
1990- Bachelor’s Course: Psycho-Social Changes in Aging
Department of Social Work, Université du Québec à Montreal
1988 Lecturer – Bachelor’s Course: Travail social et personnes âgées ; Personnes âgées et société.
Cegep Bois-de-Boulogne, Cegep Marie-Victorin and University of Montreal
1985 Professor – Adult Education Courses
CHC Québec, Programme d’aide aux employés
1993 Consultant
Specialty in gerontology, home care and abuse & neglect of older adults

RESEARCH GRANTS AWARDED
1990-present Several grants awarded to NDGCCEA by New Horizons and Provincial government of Quebec for programs on prevention of Elder Abuse.
1998 Rinfret-Raynor, M., Nahmiash, D. And Firbank, O.: Impact sur les familles de la prise en charge de personnes dépendantes en regard des conduites à caractère violent. Award of 58 000 $
1998 Canadian Home Care Association, Best Health Practise Models of Self-Managed Care: Their Application for Seniors, Population Health, Health Canada, 48 690 $ for 19 months.
1997 Nahmiash, D.: Evaluation of Home Care Programs, Mc Gill Centre for studies in aging, 30 000 $. Drummond and Gustav Levinschi Foundation and Fondation de l’Âge d’Or.
1996 Nahmiash, D.: Prévention, Reduction and Stopping of Abuse and Neglect of Older Canadian Adults Living in the Community. Forum national sur la santé, Santé et bien-être social Canada, 5 000 $.
International Collaboration

1994  Guest professor in Japan College of Social Work by Heiwa Nakajima Foundation. Four conferences and a research study compared homecare services in Japan with Quebec: A comparison of Social Welfare Services in the Community in Japan with Quebec. I continue my collaboration with Dr Ruriko Takahashi from Japan College of Social Work.


Reviews and Journals

Canadian Journal on Aging, Editor of Social Policy & Practise Section.
CASSW.
World Association of Gerontology
Geronto-McGill, Journal of the McGill Centre for Studies on Aging, Member of the Editorial Committee.
NHRDP, Federal Research Grants Committee Consultant
National Action Plan to Reduce Elder Abuse in Canada.
Seniors Education Centre, Saskatchewan, Module de sensibilisation à la vieillesse maltraitée.
Canadian Association in Home Care.
Revue de recherches féministes.
Revue Anthropologie.
Revue Service social.

Provincial and Federal Committees

1990-91  Quebec Government, Report and Review on Abuse & Neglect of Older Adults

1989-90  Pelletier Committee, Quebec Government, Member of expert committee recommending policies for services to seniors in Quebec, Review and Production of a report.

1989  Canadian Association in Home Care. President of research committee.
Clinical tools for case management.

Daphne NAHMIASH, Ph. D

Member of National Seniors Council of Canada

Introduction and rationale

Case management mechanisms are most important for planning effective and efficient services for vulnerable people and persons with complex physical and psychological problems including those suffering from dementias of the Alzheimer type. These are especially essential in countries such as Canada and France whose populations are rapidly aging. In Canada, because of gains in life expectancy at age 65, old age spans a longer period of time. Between 2006 and 2026, the number of seniors aged 85+ is projected to increase from about 500,000 to 900,000 according to Statistics Canada (2007). Dementia, including Alzheimer’s disease is a problem that increases with age after 65 years and with the aging of the baby boom generation, the number of persons with dementia will increase significantly over the next three decades. New models of care need to be developed using broader case management strategies. The Canadian National Home Care and Primary Health Care Partnership Project was funded by Health Canada’s Primary Health Care Transition Fund to examine a broadened scope of home care in chronic disease management, by moving from a traditional case management model where activities were focussed on the client’s episodic needs to an approach which considered the client’s experience in the context of their broader needs across the health care system and that worked in productive collaboration with the primary care teams and all health care team members worked to maximize client wellness and autonomy through advocacy, communication, education, identification of and access to necessary resources and service coordination. This project demonstrated the benefits of an enhanced role for home care case managers in the management of individuals with chronic diseases. This included -:

- Regularly assessing disease control, adherence to care plan and self-management status
- Either adjusting treatment or communicating needs to primary care physicians immediately
- Providing support for self-management
- Providing for more intense follow up
- Providing navigation through the health care process.
Thus, there is an increasing need to find more effective case management services, models and systems to best serve and manage this increasingly large number of persons with extremely complex needs and diseases.

**Case Management Definitions**

The scope of case management can be very broad, as it encompasses community-based programs, such as home care, child health services and mental health clinics. Since case management is mainly practiced by nurses and social workers and some rehabilitation therapists we will note some key definitions used by these disciplines and in particular those who work with the elderly.

Nursing articles have stated that nurse case management has become the popular Canadian strategy for coordinating health and community-based home care services to the frail elderly and other target groups, who are at high risk and have complex needs. Case Management is stated to be the provision of an integrated system of care for individuals with long term, complex health and social needs and has still not been fully achieved in Canada, although many provinces have made considerable progress toward achieving these goals. Case Management is also considered as a method of integrating and coordinating health and social service systems by many developing countries. Central to the effectiveness of case management is the role of the case manager, who provides clients with consistency, continuity and coordination of care across all clinical settings and boundaries. Comprehensive case management practice involves recruitment and training of professionals with the knowledge and skills to work within bureaucratic and organisational service systems (Gutman, 1999).

In the document entitled Social work best practice healthcare management standards, case management is described as a method of providing services whereby a professional social worker collaboratively assesses the needs of the client and the client’s family, when appropriate, and arranges, coordinates, monitors, evaluates and advocates for a package of multiple services to meet the specific client’s complex needs. The practice of case management varies greatly across social work settings and is even more diverse as applied by other disciplines (NASW Standards for Social work case management, 1992).

The Canadian Association of Rehabilitation Professionals defines case management as a systematic process merging counselling and managerial concepts and skills through the application of techniques derived from innovative and researched methods. The professional’s role is to interview, counsel and plan rehabilitation programs, coordinate services, interact with significant others and place and do follow up with clients monitoring their progress and solving their problems. Finally the Canadian Home Care Association defines case management as “a collaborative client-driven strategy for the provision of quality health and support services through the effective and efficient use of resources in order to support the client’s achievement of goals”. They also emphasize the client’s responsibility in the process “Case Management is a collaborative strategy undertaken by healthcare professionals: and indeed a strategy that clients themselves employ to varying degrees depending on their context. The objective is to maximize client wellness and autonomy through advocacy, communication, education, identification of and access to necessary resources and service coordination”.

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Guiding principles, key elements and outcomes of case management strategies are also described in detail. Assessment and care coordination are key elements of all home care programs and impact on eligibility requirements and allocation of services. Before looking specifically at what tools are required or used in case management strategies it could be useful to note the desired measurable outcomes of such a strategy as outlined by the National Case Management Network of Canada and endorsed by the Canadian Home Care Association in their document on standards.

Outcomes of a case management strategy

- Case management is a strategy directed toward achieving clearly defined goals
- The ability of the client/caregiver to make progress toward their goal
- The improvement of the overall effectiveness of health care services through collaboration with the health care team to increase appropriate utilization of services and reduce duplication and gaps and barriers to services
- Delivery of the right services at the right time and decreased duplication of services
- Reducing hospital/emergency utilization and delaying premature hospitalization
- Achieving client goals and improving clients’ health status and satisfaction
- Decreasing caregiver burden
- Improving collaboration and connectivity across the health care system
- Increasing health care provider satisfaction
- Improving disease management and resulting savings to the health care system

Review of some international and Canadian literature on measured outcomes of Case management strategies

A brief overview of the scientific literature enabled us to take a look at some of these outcomes to see what has been demonstrated through measuring outcomes of case management strategies. Decision-making related to resource allocation in home care management practice has been addressed by Fraser and Strang in 2004 and issues arising include the ethical dilemma of deciding the equitable and fair distribution of resources related to the provision of appropriate levels of service; economic factors related to limited financial resources and the variance of case managers in their decision-making about such resources.

Health Canada reports that case management projects in Newfoundland and Labrador, Nova Scotia and Prince Edward Island have increased program efficiencies and staff productivity. In Nova Scotia and Prince Edward Island efficiencies were created in the service delivery system with the results that more provider time could be devoted to service delivery as efficiencies were captured through the technology for inputting and accessing the forms used. There is also increased information available for policy makers, planners and researchers as a result of the projects. Information from operational databases is now available through the development and implementation of decision support systems thus moving many of these programs to a better basis for evidenced-based decision making (Health Canada, 2003).
A third journal article reported that older people receiving nurse case management coping assistance interventions demonstrated an increase in the instrumental activities of daily living functioning of the elders although they had lower general health, role-emotional and mental health scores (Schein et al. 2005). An additional nursing article found that case management has a positive effect on nurse-client relationships and nursing professionalism (Rheaume et al. 1994).

Another important area of outcome research looks at how case management reduces visits to hospital emergency departments in British Columbia (Pope et al. 2000). The authors describe a case management program for frequent users of the emergency department over a 12 month period before referral to the program and a similar period after implementation of an individualized care plan by a multi disciplinary team. Referrals were made based on them having two or more of the following criteria:-: a chronic medical condition, a complex medical condition, drug seeking behaviour, violent behaviour and abusive behaviour. For the 12 month period before referral, the 24 selected clients accounted for a total of 616 (median 26.5) visits to emergency; for a similar period after, they accounted for only 175 (median 6.5) visits. Thus, this program appeared to be effective.

A study in Alberta examined the use of clinical case management for early stage Alzheimer patients and their families (Chu et al., 2000). The study provided comprehensive home care services to persons with early stage Alzheimer’s disease and their primary caregivers over a period of 18 months. Results showed that caregivers in the treatment group felt less burdened than caregivers in the control group and institutionalization was delayed for patients with mild to moderate impairment in the treatment group. These differences seem most attributable to the case management services provided to persons in the treatment group which featured supportive counselling, referral, skill training and education. Another study in the US found that case management reduced hospital admission in caregivers of people with Alzheimer’s disease (Shelton et al. 2001) when case management consisted of comprehensive, in home, clinical assessments that were updated every 6 months. Nurse case managers identified client and caregiver medical and psychosocial problems and service needs and developed a care plan with the agreement of the caregiver and client and the added community care benefits reduced health care resource use and Medicare payments.

A meta analytic review by an international team synthesizes the results of 24 studies dealing with the effectiveness of case management with the severely and persistently mentally ill (Gorey et al. 2004). They found that overall the case management interventions were effective in that 75% of clients in the programs did better than those not in the programs; the estimated prevention fraction (e.g. Prevention of rehospitalisation) among clients experiencing intensive case management programs (case loads of 15 or less, 89%) is 30% greater than those using less intensive services; and finally, various case models did not differ significantly on estimated effectiveness.

A report by Veterans Affairs Canada in 1999 states that single entry, coordinated assessment and case management strategies lead to increased efficiency and help ensure that people receive the appropriate level of care in the community. Common assessment tools and classification systems, coordinated case management and effective management and the capacity to plan at a system-wide level combined with a political will should help the long term care sector to reach its full potential. The report also notes issues related to caregivers as
more women will be providing increased amounts of care giving in the future, thus care for the
caregiver cannot be overlooked or the need for respite care.

A medical study related to case management demonstrated that for a modest cost a case
manager was able to substantially increase rates of osteoporosis treatment (Sumit
R.Majumdar et al. 2007) in a vulnerable elderly population at high risk of future fractures.

We can conclude from this review that several outcomes of case management strategies
have been measured and many have successful and positive results from the use of effective
case management strategies with the elderly and mentally ill population.
We will next concentrate on the benefits and disadvantages of using clinical tools by
professionals in case management.

**Clinical tools used in Canadian programs for home based care for the elderly**

The National Case Management Network of Canada has identified clear standards of case
management which include client identification and eligibility for case management services,
assessment services using a structured process, service planning guidelines and procedures
and implementation of planned services, resources and supports. As well, they include
guidelines for periodic reassessments to identify the client’s current needs and to monitor
progress within the client’s individualized service plan. A further section on transition implies a
process and guidelines which support disengagement or a shift in the mechanisms for
achieving client goals. They note in the same section that “while each provincial and territorial
home and community care program differs in scope, access and content, the single unifying
element of all programs is case management”. One of the guiding principles for case
management in Canada is that it incorporates evidence –based practice to ensure quality
care and outcomes and that case management is respectful and collaborative, engaging the
family and community resources for needed support.

In terms of eligibility for case management services all reports and articles support the view
that case management services are aimed at targeting clients with complex profiles but the
Canadian Home Care Association recommends broadening the eligibility criteria for home
care in order to proactively support clients to better manage their specific conditions as well
as aligning home care case management with primary health care teams including frontline
clinicians and family physicians. At the same time they emphasize using assessment tools to
automate and improve consistency of the assessment process and communication of the
results to those concerned in the care of the client. They also recommend the use of chronic
disease tools that reflect agreed upon care algorithms to improve consistency of care across
the primary health care team. In the demonstration, changes of patterns of practice were
experienced through the partnerships which benefited the clients. For example, they cite that
the more time case managers spent educating, monitoring and navigating to ensure that
practice guidelines and algorithms are adhered to, the greater the statistical likelihood that
clients saw improvements in outcome metrics and client satisfaction.

A variety of assessment tools are used regionally to determine client needs and subsequent
care plans including provincially specific assessment tools, as well as international data
collection tools. One of the tools selected by the majority of jurisdictions is the Resident
Assessment Instrument for Home care (Inter RAI-HC) which was designed to identify client
needs, using the Minimum Data Set for Home Care (MDS-HC). The clinical assessment
protocols and the outcome measures that were developed within InterRAI are used to inform
decision making at the client level. Care planning protocols and outcome measures were
designed to enable case managers and health care professionals to assess an individual client’s needs, allocate services and track how the client does over time. The quality indicators and organizational level measures are a direct result of the client level decisions. The province of Quebec uses different assessment tools named the OEMC and the DSIE. The rest of this report will therefore focus on the strengths and weaknesses of these assessment tools as possible tools for use in France in home care programs addressing the frail elderly and persons suffering from Alzheimer’s’ disease.

1. Inter RAI-Minimum Data Set Tool

The researcher John Hirdes (2006) notes that people with complex health needs present symptoms that are often ambiguous, threats to health are often multi factorial, trajectories of change are highly variable and outcomes of care are uncertain. Thus, we need tools which provide comprehensive assessments yielding high quality, multi dimensional information to provide care at the individual level and he cites the MDS tool as useful for this goal. Johnson and his colleagues propose the use of the MDS –AC assessment to this end.

The Long Term Care Minimum Data Set (MDS) is a standardised, primary screening and assessment tool of health status that forms the foundation of the comprehensive assessment of all residents in certified long term care facilities. It measures physical, psychological and psychosocial functioning. The MDS provide a multidimensional view of the client’s functional capacities and helps staff to identify health problems. In 2002, Nova Scotia was the first province to select Momentum Healthcare software to implement a computerized home care MDS assessment system to support intake, assessment and long term care wait list management as part of Nova Scotia’s innovative Single Entry Access(SEA) project to support 300 Care coordinators (case managers) in the province. MDS for homecare is rapidly gaining recognition as the standard resident assessment instrument (RAI) for home care. It is also widely used in other provinces such as Ontario, British Columbia and Manitoba. It captures essential data that becomes the foundation for improving the quality of life for home care clients. The RAI-HC was developed by a consortium of 30 university-based researchers from 20 countries around the world and consists of a series of compatible, standardized assessment instruments to be used across multiple home care settings that serve the public.

In addition to the assessment, the software automatically calculates the Client Assessment Protocols and problem triggers (CAPS), Resource Utilization Grouper-classification system (RUGs111), DIN (drug identification number, International Codes for Disease/Diagnosis), allergy tracking, electronic data submission and remote assessment capability, all of which can provide client profiles for provincial planning of services.

In the RAI, Home care was mandated for all home care clients expected to be on service for 60 days or more. Case Managers in single point entry agencies, known as CACCs, now use this form to assess needs and to contract services for home care clients. In 2005 the RAI-Mental Health was mandated for use in all adult in-patient beds in psychiatric hospitals/units, including acute, long stay, forensic and geriatric psychiatry. Implementation of the RAI 2.0 is currently underway for all long term care facilities in the province of Ontario including for profit and not- for- profit homes. A contact assessment (interRAI CA) is developed also for use as the initial brief assessment of all CCAC clients and short stay home care clients to determine the need for a comprehensive assessment with the RAI-HC, the urgency for initiation of services such as nursing or personal support, and need for referral to rehabilitation services. The software supporting the instrument is accessed using a laptop computer to support the care coordinator in the field. The care coordinator can use the information to make a
recommendation for placement to a variety of continuing care services. The clients targeted are those with loss of autonomy regardless of the site and sites include clients in acute care, long term care and assisted living facilities as well as in home care.

**Strengths of the MDS instrument**

The advantage and strengths of the MDS tool is that it provides an excellent data base of clients and family or primary caregivers with complex problems which is comparable and measurable across various sites and it uses flags which remind health care providers to check protocol use for certain types of care and disease treatments or gives warnings about health care information or needed revisions and updates. As a result of the extensive use of the MDS RAI tools in Ontario and 7 other provinces and territories, the Canadian Institute for Health Information has established three national reporting systems to provide comparative reports on continuing care, homecare and mental health. A national users Forum has also been established as a venue through which clinicians, using these instruments, exchange knowledge on their implementation and use in day-to-day practice.

Other strengths are resulting good assessment practices within individual health care sectors and effective exchange and utilisation of information between sectors collaborating in providing care to the targeted frail elderly clientele.

Strong leadership at all levels of the health system; effective collaboration between stakeholders; commitment to standardisation based on psychometrically sound data and the establishment of an infrastructure to capture, compile and report on the gathered data are required to implement a new standardised instrument. Some challenges are also noted by Hirdes-:

- The introduction of any standardised instrument is a major perturbation to the health care system that requires appropriate resources and effective change management processes;
- The availability of computerised information systems is a prerequisite to successful implementation;
- Education of clinicians, managers and policy makers in the use of the instruments and the data they yield must be provided on an ongoing basis;
- Feedback is critical for all stakeholders. The data must be used to inform decision making at all levels of the health care system and
- Although the data can be used for many purposes, there must be a clear emphasis on their clinical applications to sustain their use in daily care provision.

The weaknesses of the tool are that they need to be continually audited correctly and health care providers need to use the training manuals appropriately and update them regularly. As well, data about quality of care is hard to numerate and hard to measure, which is a weakness of all computerised tools as people and problems do not always fit into specific categories and coding systems. Another weakness is the lack of definition of the targeted...
clientele and how a complex client is defined or who are the clients with a loss of autonomy, as some programs use a broader definition than others.

Regarding implementation of a new standardised instrument for the frail elderly, resistance to change, unfamiliarity with new assessment procedures and clinical terminology, limited computer literacy, introduction of data submission standards and reorganisation of business processes to eliminate unnecessary documentation are all issues which need to be dealt with.

In addition, auditing systems are often not used effectively. Even though hospital audits are made public and hospitals are ranked according to their audits with the data providing some accountability to the public as well as to the policy makers and planners; the system is not fool proof, as sometimes hospitals hire companies to make their statistical records look better than they really are.

Assessment instruments used in Quebec-OEMC and DSIE

The Outil Evaluation Multiclientele (OEMC) Instruments are used in the province of Quebec by all home care programs and case managers (nurses, social workers or rehabilitation therapists) to assess homecare clients who include all persons with a loss of autonomy (the majority of whom are over the age of 65) for the allocation of services and to provide an individualised service plan for each assessed client.

The multi clientele intake procedures include socio demographic information; source of request; statement of request; medical information about current resources; comments and additional information; identification of risk factors; decision regarding request; priority to assess the situation further and steps taken at the time of contact and recommendations.

If there is a decision for referral the multiclientele assessment form is completed. If a referral is required to another establishment or to a different department within the same establishment, such as to the home care program the DSIE (Demande de Services Interetablissements) form is completed on the computer. These forms are shared with hospitals, longterm care facilities, or another CLSC if the person lives in or moves to a different territory or a rehabilitation center. The tool is clinical, can go in both directions i.e. information can be shared back and forth between the establishments and targeted at medium or long term home care clientele. It uses a software program called Lotus notes. Information can be updated on the tool and automatic updating of medical information such as allergies, previous medical and surgical history on a person asking for services and can be sent to several places at once.

Multiclientele Assessment tool (OEMC).

It should first be noted that the international Prisma research team of Somme, Bonin, Lebel, Hebert and Blanchard have done important work on the development and adaptation of the individualised service planning tool which helps case managers plan, monitor and coordinate services and is an important part of the Multi Clientele Assessment tool (Somme et al. 2009). The tool targets a variety of clientele with physical or mental impairments or diagnoses of mental illnesses and is validated enthusiastically by case managers and health care professionals using it. The tools are used in the research model PRISMA for all organisations.
including public, private, volunteer and community services and aim to provide coordination at
all levels of decision making, a single point of entry system, case management, individualised
service plans, a unique standardised assessment tool and a computerised clinical chart. Case
managers in Quebec are all under the responsibility of and remunerated by the public health
care and social services system.

The Multi Clientele Assessment tool consists of 18 pages and provides an evaluation of the
functional autonomy of the client. It is divided into ten sections and subsections which include:-
State of Health-personal and family health and current diagnoses, physical health,
psychological health, medication (prescribed or not) and health services; Living Habits-
nutrition, sleep, tobacco use, alcohol and drug use, personal and leisure activities; Activities
of Daily living- eating, washing, dressing, grooming, urinary function, bowel function and
toileting; Mobility-transfers, walking inside, installing prosthesis or orthosis, propelling a wheel
chair inside, negotiating stairs and getting around outside; Communication-vision, hearing,
speaking; Mental Functions- memory, orientation, comprehension, judgement, behaviour;
Instrumental Activities of Daily Living-housekeeping, meal preparation, shopping, laundry,
telephone, transportation, medication use and budgeting; Psychosocial Situation- social
history, family situation, main caregivers, social network, community public and private
resources, affective state, users impressions, sexuality and personal, cultural and spiritual
beliefs and values; Economic conditions-capacity to meet financial obligations with current
income; Physical Environment-housing conditions, personal and environmental safety,
accessibility, proximity of services; Summary-context of assessment, urgent problems
identified, users expectations, risk factors and suggested orientations. The last part of the
Multiclientele form is the Multi clientele Intervention and Service Plan which has been studied,
adapted and validated by the PRISMA research team. This consists of naming goals for the
client, family and friends followed by the Intervention and Service allocation Plan (both
interdisciplinary and unidisciplinary) noting each problem and intervention objective and
revision dates. Some current professional health care workers using this tool identified some
strengths and weaknesses observed.

**Strengths of the Multiclientele tool**

- In general the tool is found to provide a good functional assessment of the client's
  autonomy from a bio, psycho, social perspective
- It enables revisions and adjustments for those with difficulties
- It has not all been computerised but there are plans for this (already computerised for
  Sherbrooke and Laval)
- Some adjustments and mistakes can be picked up if the codes are not completed
  correctly if an euclicienne distance is shown (i.e. if code numbers are over 5)
- The tool is comprehensive and provides a picture perfect image of who the client is,
  especially in cases of persons over the age of 65 years
- It provides a good varied colour coded profile of the clients, 1-14 levels of care (level 1
  and green being the most autonomous). Variations between level 8 and level 9 could
  be additional behavioural issues to help understand the client
- Good training programs exist from a central place (they last 1 and a half to two days)
• There is a good training manual with specific examples shown
• Each organisation (CSSS) has their own trainers.
• Information is shared with Long Term care Homes and Long term Home Care staff.

Weaknesses of the tool

• The sections on sexuality, drugs and alcohol/medication abuse is not always completed well by personnel who are not comfortable asking the questions
• The tool is less appropriate for clients under 65 years according to the trainers. It is better for clients with a loss of autonomy due to the aging process
• Health care professionals complain about duplication of information in the tool
• The tool takes time to complete and needs practice to comprehend it well as there are exceptions to some of the rules (i.e. If a client takes a B12 shot once per month they would go from a 0-2 even if they are completely autonomous)
• Evaluators do not always evaluate the same way
• Clients do not always fit into exact categories.

We would also add that for specific problems the nurses and social workers still feel the need to use additional tools and protocols, for example to screen and assess family caregivers, such as, the Guberman et al. Screening and assessment tools for assessing clients with moderate, severe or mild mental illnesses, including those with Alzheimer’s disease, for example, the MMSE (Mini Mental status Exam of Folstein) or the MOCA (Montreal Cognitive Assessment ) tool (in cases of mild cognitive impairment). As well, clinical tools are used across Canada to screen and identify elder abuse, such as, the Reis-Nahmiash CASE (Caregiver abuse Screen) and IOA (Indicators of Abuse).

Conclusions

Our conclusions after reviewing the clinical tools are that no tool is perfect but the MDS-HC/InterRai-HC and the Multiclientele tools are the most fitting for client assessments and intervention planning for use in case management programs and could be recommended for use in France with Alzheimer’s clients and others. However, all tools are dependent upon good auditing systems to ensure they are used in a standardised way and the information is used appropriately to understand and improve the client services as well as for accountability. All tools and systems are only as consistent as the training programs, trainers and training manuals (with examples) in place and the health care professionals using them and revising them as needed.
Clinical tools for case management.

Daphne NAHMIASH, Ph. D

**STRENGTHS**

- Method of and provides integrated system of care for clients with long term, complex health and social needs
- Measurable and comparable outcomes across sites
- Two international computerised clinical assessment and planning tools - Inter RAI and OEMC
- Reminds providers to check protocol use for types of care and disease treatments
- Issues warnings about health care information and revisions needed (InterRai –HC)
- Provides comprehensive functional assessment of client from biopsychosocial perspective
- Provides excellent exchange of information opportunities.

**WEAKNESSES**

- Must be audited correctly
- Professionals need to use training manuals appropriately
- Some programs define more broadly who is eligible for services or client with loss of autonomy
- Some areas of the tools not completed well due to comfort level of asking questions re sexuality, drug/alcohol/medication use
- There is some repetition on tools (OEMC)
- Clients do not always fit into exact categories
- A variety of additional tools need to be added for certain clients (ex. Mental health tools re dementia, abuse screening and assessment tools and a more comprehensive screening and assessment caregiver tool).

**OPPORTUNITIES**

- Tools offer the opportunity to provide standardised assessments and care plans across public and private systems.
- Provide measurable outcomes
- Tools offer a data base for policy makers, planners and decision makers for allocation of resources related to appropriate levels of care
- Use of standardised tools and auditing systems result in good assessment practices, effective exchanges and utilisation of information between sectors collaborating in providing care for the frail elderly.

**THREATS**

- Introducing any standardised instrument is a major perturbation of the system
- Requires appropriate leadership, resources and effective change and management processes
- Availability of a computerised information system is a prerequisite
- Education and training on an ongoing basis in use of instruments and the data they yield
- Feed back is critical and data must be used to inform decision makers at all levels
- Need to have a clear emphasis on the clinical applications of the data to sustain their use in daily care provision

*Case Management – 8 & 9, March 2010*
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PERSPECTIVES OF THE CASE MANAGEMENT IN FRANCE

MAIA EXPERIMENTING

Speaker:

Olivier DUPONT, CNSA

1. QUALIFICATIONS
- Doctor of medicine: medical qualification 1989
- Ability of clinical gerontology (Paris VI): 1989
- Hospital Practitioner: 2000
- Physician Assistant Service Long Term Care Institutional. Since 1995

2. FUNCTIONS PERFORMED
1. Functions performed as holder
- Medical Coordinator nursing home Cergy-Pontoise /Conception of Alzheimer's Unit 1990-1991
- Physician responsible for the study SEGISS (Society study and management of health and social institution) Participates in the development projects of establishment of Hospital: Morteaux, Orgemont, Rambouillet. 1990-1991
- Physician Assistant Nursing Home Private nursing home Bellefontaine 95 1993-1997
- Hospital Practitioner, Department Head. Care service after rehabilitation, pathology neuro-vascular - palliative care- and geriatrics. CHG. Senlis Oise 1997-2004
- Physician. Center for Geriatrics Long Term Care Condé Geriatric Center. Private Hospital Chantilly Oise since 1995
- Physician and team manager in health maintenance organizations during 3 years Gerontologic Health organisation in Picardie/Oise
- Working for the Health ministry, responsible for mission-Pathology and Public Health "chronical disease and aging" Ministry of Health, Youth and Sports Working on Alzheimer national program, Palliative care, Healthy ageing And PRISMA france project
2. Currently
ROUND TABLE & SYNTHESIS

Chair:

Joel MENARD

MEDICAL ACTIVITIES SINCE 1980
1981 - 1986 Head of the Hypertension Clinic, Broussais Hospital, Paris.
1989 - 1997 Head of the Cardiovascular Preventive Medicine Center at the Broussais Hospital, Paris.
1997 - 1999 Chief Medical Officer at the Ministry of Health.

UNIVERSITY TITLES AND FUNCTIONS
1989 - 1997 Professor of Internal Medicine, Faculty of Medicine, Broussais-Hôtel Dieu (Paris VI University).
1999 - 2008 Professor of Public Health, Faculty of Medicine Paris-Descartes.

SCIENTIFIC ACTIVITIES
1983 Invited Scientist, Laboratory of Immunology, Ciba-Geigy, Basel (3 months).

PRIZES AND SCIENTIFIC AWARDS
1981 Claude Bernard Award, City of Paris.
1984 European Mac Foster Award, European Society of Clinical Investigation.
1985 Ciba Award, American Heart Association (US).
1994 Von Humboldt Research Award (Germany).
1997 Association Française de Recherche Thérapeutique.
2005 Paul Milliez Award, European Society of Hypertension.
2007 Prix Danièle Hermann, Fondation de France.

PHARMACEUTICAL INDUSTRY
1986 - 1989 Head of International Clinical Research and Development, Ciba-Geigy, Switzerland.
2000 Scientific Council, Actelion, Switzerland.
2006 Cardiovascular Consultant, Novartis.

ADMINISTRATIVE ACTIVITIES
1980 - 1986 Member of the Committee on Cardiovascular Diseases, Ministry of Health, Paris.
1984 - 1986 Technical Adviser near of the Secretary of State for Universities, Ministry of National Education.
1990 - 1995 Member of the Clinical Investigation Committee, INSERM.

MEMBERSHIP OF SCIENTIFIC SOCIETIES
- European Society of Hypertension (Board 1995-1998).
- French Society of Nephrology, member.
- American Society of Hypertension (Board, 1996-1998).
- International Society of Epidemiology, member.
8th & 9th March 2010

Partners
Thomas RAPP is a Research Fellow at the French National Institutes of Health and Medical Research (INSERM U558) and Gérontopôle of Toulouse. His areas of interest include health economics, health disparities, long-term care policy, and financial economics. He received his M.A. and Ph.D. degrees in Economics from the University of Paris Dauphine, Department of Economics.

He did his postdoctoral fellowship at the University of Maryland, Department of Pharmaceutical and Health Services Research. As a fellow, he acquired an applied specialization in pharmacoeconomics and outcomes research. He is a member of the International Society for Pharmacoeconomics and Outcomes Research, the Advancing Science Serving Society, and the FONDACT scientific board. Thomas Rapp lives in Toulouse (France) with his wife and daughter.
A SHORT REVIEW
Case Management in Alzheimer’s Disease

Thomas RAPP, PhD

Abstract: In this short review, we describe foreign integrated care systems and case management experiences. In order to have a broader view of case management experiences in foreign countries, selected publications do not focus only on case management in Alzheimer’s disease. However, selected papers describe interventions on frail, elderly patients. We focus on the following themes: organizational context and economic analysis, professional practices, and clinical tools. For each theme, we identify important questions needing answers before implementing the Fifth Measure of the French Alzheimer Plan (see appendix for a description). Our goal is to provide practical answers to these questions, using results from the academic literature.

BACKGROUND

Context

Alzheimer’s disease (AD) is a neurodegenerative disease that affects patients’ cognitive capacities and abilities to perform activities of daily living. As a large proportion of patients with AD live at home, informal (unpaid) care remains the largest resource used (1). A lack of access to health care resources, fragmented services, and disjointed care lead to system inefficiencies, lack of quality, and cost explosion (2, 3). In that context, there is need for integrated care systems where professionals trained in Alzheimer’s disease case management (4) would provide assistance to patients and their informal caregivers.

Definitions

According to the Case Management Society of America, case management (CM) is “a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual’s health needs through communication and available resources to promote quality cost-effective outcomes” (4). CM is usually part of an integrated care system, which can be defined as a “discrete set of techniques and organizational models designed to create connectivity, alignment, and collaboration within and between the cure and care sectors at the funding, administrative and/or provider levels” (5).

1 Fondation de Coopération Scientifique Maladie d’Alzheimer et maladies apparentées, INSERM U558 and Gérontopôle of Toulouse. Email : rapp@cict.fr
Case management in the French Alzheimer Plan

The Fifth Measure of the French Alzheimer Plan is dedicated to the implementation of CM in France (6). Case managers’ mission will be to evaluate patients’ need and provide individualized care plans. Case managers will coordinate and manage patient care in hospital, home, long-term care, rehabilitation, mental health, and managed care settings.

Foreign experiences of CM

Before implementing the Fifth Measure, it is important to explore foreign experiences. Most of CM interventions are found in North America, where several projects have been developed. A non-extensive list of projects and studies in the United-States would include the Medicare Alzheimer’s Disease Demonstration (MADDE) (8), the Alzheimer’s Connections Demonstration Programs (9), the Palliative Excellence in Alzheimer Care Effort (PEACE) (10), and the Program of All inclusive Care for Elders (PACE) developed at On Lok and then replicated across the whole country (11-19). In Canada, two main integrated care programs can be identified: the Programme of Research to Integrate Services for the Maintenance of Autonomy (PRISMA) (20, 21) and the Systèmes de soins Intégrés pour Personnes Agées (SIPA) (22, 23). In Europe, CM is developed in Finland, Iceland, Italy, Sweden, and in the United Kingdom (24, 25).

Objectives of the review

The goal of this short review is to describe foreign integrated care systems and CM experiences. We focus on the following themes: organizational context and economic analysis, professional practices, and clinical tools. When possible, we compare the Fifth Measure of the French Alzheimer Plan to recommendations from foreign experiences.

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2 A reason for this large interest could come from the fact that the United-States can be described as “largely dependent on informal caregivers for the community care of those with Alzheimer’s disease” 7. Arnsberger P, Fox P, Zhang X. Case manager-defined roles in the Medicare Alzheimer’s Disease Demonstration: relationship to client and caregiver outcomes. Care Manag J 1999;1:29-37

3 The PEACE program is a “disease management model for dementia that incorporates advance planning, patient-centered care, family support, and a palliative care focus from the diagnosis of dementia through its terminal stages.” 10. Diwan S, Hougham GW, Sachs GA. Strain experienced by caregivers of dementia patients receiving palliative care: findings from the Palliative Excellence in Alzheimer Care Efforts (PEACE) Program. Journal of palliative medicine 2004;7:797-807
ORGANIZATIONAL CONTEXT AND ECONOMIC ANALYSES

Where are CM interventions implemented?

The Fifth Measure of the French Alzheimer Plan says that CM will occur in the *Maisons pour l’Autonomie et l’Intégration des malades Alzheimer*, which will employ case managers. The underlying idea is to develop CM within a coordination model rather than to implement CM in a full integration model. Hébert and colleagues (20) provide an useful description of integrated models:

**Figure 1. Comparison of two models of Integrated Service Delivery**

<table>
<thead>
<tr>
<th>Coordination model [PRISMA]</th>
<th>Full integration model [SIPA, PACE, CHOICE]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single entry</td>
<td>Entry</td>
</tr>
<tr>
<td>Triage</td>
<td>Case-Manager Multidisciplinary Team</td>
</tr>
<tr>
<td>Home Care</td>
<td>+/- Day Centre</td>
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<tr>
<td>Case Manager</td>
<td>+/- Home care</td>
</tr>
<tr>
<td>Long-term Care Inst.</td>
<td>Hospital &amp; Rehab.</td>
</tr>
<tr>
<td>Hospital &amp; Rehab.</td>
<td></td>
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</tbody>
</table>

*Source: Hébert et al. (2003)*

*Legend: continuous-lined boxes → organizations are independent in their structure and management; dotted-lined boxes → part of the organizations autonomy is transferred to the integrated structure.*

Coordination models have a single entry point (telephone or written referral) for patients receiving the intervention (20, 21). According to Hébert and colleagues (20), coordination “involves the development and implementation of defined structures and mechanisms […] where every organization keeps its own structure but agrees to participate in an “umbrella” system and to adapt its operations and resources to the agreed requirements and processes”. Fully integrated systems do not necessary have single entry⁴. As described in Hébert and colleagues (20), full integration involves that “services are delivered by structures operated by the system or by external structures through contract (hospitals, specialised medical care, long-term care institutions)”.

⁴ Kodner and Kyriacou raise a concern on the transferability of the two main US fully integrated systems (social HMO and PACE) to other countries, even if “this does not seem to be a totally insurmountable barrier witness the planning and development of the SIPA system” 26. Kodner DL, Kyriacou CK. Fully integrated care for frail elderly: two American models. International journal of integrated care 2000;1:e08.
Which size for CM interventions?

There is no “golden rule” for CM intervention size, e.g. intervention length, number of participants, and caseload per case manager. Depending on the study, intervention length varies from six months (27) to more than ten years (28), while the participants number ranges from thirty to more than five thousand participants in the case of the MADDE studies (29-32). The small size of some integrated care models program sites (around 300 participants) would guarantee intensive and effective interventions (26). Indeed, most interventions involve important degrees of personalization, as cultural factors are likely to influence intervention results (33, 34).

The French Alzheimer Plan has an objective of training 1,000 case managers by 2012, which will be providing care coordination nationwide5 (6). In other countries, intervention intensity usually depends on disease severity (35): 1 case manager for 100 patients with high severity (phone calls + home visit), and 10 case managers for 6,000 to 7,000 patients with mild severity (phone calls only)6. For patients with light diagnosis, email/mail contact only is recommended. In the National Health Service (NHS) program, caseload per case manager is 50 patients. In the Darlington project, the caseload is about 20 patients per case manager (36).

Another question that can be raised deals with the territorial size of CM practices. Interventions can be provided at either the patients’ home (37), or in adult Day Care centres (26). Mostly, interventions rely on University Clinics structures (27, 38), community sites (39) or Alzheimer’ Association Chapters (9). Finally, most of efficient interventions are implemented in urban areas such as New York City (40), Cleveland (41), or Hong-Kong (42).

How are CM interventions financed?

Two financial components have to be explored: funding sources and budgeting, e.g. how money is used. If case managers can be working for private companies, several CM projects rely on public funding. In the United-States, the MADDE program has been “mandated by Congress in response to awareness of caregiver problems in obtaining services to assist in the care and management of demented persons” (7). The PACE system is financed by monthly capitation payments from Medicare and Medicaid (26) and some private out-of-pocket premiums (36). In Canada, the PRISMA and SIPA systems are financed by the government (43). In the United-Kingdom, the Darlington project is financed by the government.

Budgeting strategies may vary a lot (36). In the Darlington project, case managers are in charge of allocating budgets for about 20 patients. Cost targets are defined as 2/3 of long stay hospital care costs. The PACE and SIPA integrated systems use prepaid capitated financing systems, e.g. healthcare services payments are set for each enrolled patient based upon predicted health care resources consumption. Budgeting in the PRISMA system is driven by negotiations between partners involved in the coordination of care (20). Some

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5 Based upon the estimation that between around 400,000 patients are treated for AD in France and that 5-10% of them may be eligible to CM – usually, 5 to 10% of patients consume between 25% and 30% of resources – the caseload would range between 20 to 40 patients per case manager.

6 In the Fifth Measure of French Alzheimer Plan, CM interventions should not include interventions involving only phone calls.
studies find that CM effectiveness is greater when bundled with public financial support, e.g. CM leads to greater community-based services use when reimbursements are available (31).

Despite the existence of various financing and budgeting strategies, some important questions remain unanswered. **Q1: Should CM services be bought from private companies?** US private and public insurers have chosen to buy services from private firms, assuming that competition can guarantee performance and multiplicity of choices (35). **Q2: Should financial incentives be offered to Managed Care Organizations or insurance companies willing to provide CM interventions?** Such organizations are not likely to participate in CM interventions as they are not always in charge of coping for long-term care expenditures. In consequence, financial incentives and risk sharing are important notions to consider. **Q3: Should pay-for-performance mechanisms be implemented in CM?** In the United-States, Medicare CM programs are required to provide net savings, with a -5% objective over a three-year period. However, it is difficult to determine whether short-term or long-term objectives should be targeted for savings (35). In Germany, pay-for-performance systems can be offered to general practitioners who enrol patients and participate in disease management programs (35): 20 Euros for each enrolment, 20 Euros for documenting patients’ health status, 15 Euros for providing educational training. **Q4: Should CM out-of-pocket costs be reimbursed?** Safety assessment and caregivers’ education programs can be expensive for informal caregivers, who already deal with important financial burden. To the extent that education programs could be prescribed by primary care physicians, reimbursement should be discussed.

**Are CM interventions cost-effective?**

Despite the presence of substantial academic literature on CM, its effectiveness remains under evaluated (44). Many programs did not improve quality of dementia care, and made no significant or small difference in nursing home placement and level of service and informal care use (28, 45-47). There is no clear consensus on the goal of CM interventions; depending on the intervention, CM goal has been to prevent or delay nursing home admissions, to increase the use of professional services in the community, to reduce informal caregivers’ burden and improve their satisfaction. In consequence, CM cost-effectiveness would depend on the outcomes measure chosen to evaluate its efficacy.

Few studies provide economic analyses, and most of them are limited to cost calculations of successful CM interventions (48), or to the evaluation of CM interventions impact on short-term health services utilization and expenditures (27). If cost is a very important determinant of CM use (49), there is mixed evidence that CM interventions lead to cost reduction. Several papers conclude that CM interventions rarely reduce health care costs (46, 50). Despite tendencies towards reduced expenditures\(^7\), CM could have a neutral effect on Medicare expenditures (51). A recent study evaluates that CM interventions have important start-up costs ($70,256) and annual fixed-costs ($24,162), without leading to significant reduction in costs associated with health care utilization (48). In that study, the mean societal costs (health care organization and community organizations cost) is estimated to be $118 per month per patient. Finally, some studies found cost reductions associated with CM. An Italian study provides evidence that CM interventions can lead to substantial cost reductions (37): -19% in community health services costs, -48% in nursing home expenditure, and -34% in hospital expenses. In Canada, the PRISMA and SIPA projects have been found

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\(^7\) Driven by the positive influence of community care management on health care use.

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to reduce the cost of long-term care use and to improve system effectiveness without increasing costs (23, 52).

**PROFESSIONAL PRACTICES**

*Which tasks for case managers?*

Advocacy is a central notion in case management (53), as case managers have to support and promote patients’ health care needs and rights. In the Fifth Measure of the French Alzheimer Plan, case managers should be in charge of assessing patients’ needs, preparing an individualized care plan, facilitating access to available resources, communicating with primary caregivers, and providing follow-up (in particular, for hospitalized patients).

Four main CM tasks can be identified: patients’ therapeutic education, coaching, care coordination, and follow-up (35). These four dimensions of CM can be provided in various settings, such as multicomponent telephone interventions, IT-based support, sessions of individual and family counselling, ad-hoc telephone counselling, and comprehensive support by the dementia family care coordinator (41, 54-57).

Therapeutic education has the objective to help families gain a better understanding of the disease process. It can be given through IT-based or written materials. Coaching is implemented to help patients and informal caregivers managing changes involved by the disease evolution. It can be provided through focus health care group and self-help family caregiver support groups, where participants receive assistance with problem solving. Care coordination involves evaluation of need, planning and organization of care, and reevaluation after implementation of the care plan. Care coordination has several objectives: to participate in patients and informal caregivers’ decisions, to explain and arrange professional services use, to assist in locating community resources (adult day care, in-home support or respite services), and to provide support to prepare and understand financial and legal challenges. Care coordination can be arranged in family meeting where the patients and caregivers’ needs are discussed to integrate formal and informal care (58). Follow-up is usually provided by phone calls and mail/email contact.

*How are multidisciplinary interventions structured?*

Most of interventions are provided and leaded by trained nurses (35, 38). However, CM is likely to involve the collaboration of multidisciplinary teams composed of physicians, nurses, speech therapists, and massage therapists. In some interventions, multidisciplinary teams also include nutritionists, pharmacists, personal care assistants, social workers, rehabilitation and recreation therapists, and transportation workers (26, 36). Collaborative care is found to improve quality of care and to reduce the presence of behavioural/psychological symptoms among patients and caregivers (38). Johri and colleagues (36) underline the importance of the collaboration between case managers and multidisciplinary teams, because it “ensures that geriatric evaluation is coupled with control over long-term management”.

The Fifth Measure of the French Alzheimer Plan encourages primary care physicians’ participation in CM. However, the question of the relationship between case managers and primary care physicians is very sensitive (35). Challis and colleagues (59) explain that interprofessional collaborations can face important barriers such as “professional mistrust, threats to professional identities and problems associated with information sharing”. For
instance, it can be difficult for case managers to discuss primary care physicians’ actions when they differ from CM professional recommendations (35).

However, once each professional’s functions and roles are defined, interprofessional collaborations prove to be more successful (47). In a disease management intervention designed by Vickrey and colleagues (60), the care manager “collaborated with the primary caregiver to prioritize problem areas; teach problem-solving skills; initiate care plan actions; and send an assessment summary, a problem list, and selected recommendations to the patient’s primary care physician and other designated providers”. In the three main North America integrated care programs (PRISMA, PACE, and SIPA), the primary care physician is closely involved in the service management (43). Bernabei and colleagues (37) describe a successful CM intervention where the interprofessional team is composed of a general practitioner, a geriatrician, a social worker, and nurses. In that setting, the general practitioner is in charge of performing patients’ physical examinations, which are sent to a geriatric evaluation unit who determines needed services. An individualized care plan is then designed by the evaluation unit in agreement with the general practitioner. Weekly meetings are organized to discuss home visit-related problems within the multidisciplinary team.

To prevent potential conflicts between case managers and physicians, case management organizations should (35): recognize that primary care physicians are decision-makers, have a scientific board with top-specialists, and inform primary care physicians about their good-practices recommendations.

**Which population to be targeted?**

Most CM programs use prediction models to target populations at risk (35). Some interventions occur within specific communities: Asian-Americans elderly patients (34), inner-city elders (61), and rural residents (58). The European Federation of Neurological Societies Task Force recommends providing assistance to caregivers of patients with mild to moderate dementia (62). To improve interventions effectiveness, eligibility criterions should depend on both patients’ behavioural and cognitive evaluations (63). CM should be individualized to meet caregivers’ need (47) and caregivers’ appraisals (56) and characteristics (29).

Integrated care models have various eligibility criterions that are not necessary linked to AD diagnosis. The PACE model targets volunteer community-dwelling elderly (55+) people who are eligible to nursing home admission and covered by either Medicaid or Medicare. Participants have to live in service area. The SIPA model targets volunteer community-dwelling elderly (64+) people with moderate disability. Informal caregivers have to be willing to participate in the program. Participants have to live in service area. The PRISMA model targets volunteer community-dwelling elderly (65+) people with moderate to severe disability, are likely to stay at home, need 2+ health care and social services (20). Participants have to live in service area. Some papers explain that there is need to develop greater access to CM (55); compared to patients with mild to moderate AD, most patients with most severe conditions seem to have higher benefit associated with CM interventions, with reduced institutionalization rates (57).

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8 Indeed, eligibility is not restricted to patients with AD diagnosis.
Skills and training of case managers

The Fifth Measure of the French Alzheimer Plan underlines that case managers should have specific skills and receive extensive training (6). Case managers must have good communication skills, be team players, and have empathy (35, 53). Training is very important, as there is evidence of gaps between knowledge and practice can influence intervention outcomes (50). Training should provide an extensive knowledge of the disease progression, basic knowledge of medication use recommendations in AD, and extensive knowledge of professional services available to patients and caregivers. In the United-Kingdom, the nurses enrolled in the NHS programs receive training in clinical expertise, care coordination, communication, coaching, and decision-making. Case managers usually use IT-based support to prepare their interventions (35). Depending on the nature of the intervention case managers can receive training in the use of Internet-based care management software (48).

Ethical questions

There are many ethical questions raised by CM. Because of inertia and procrastination problems, many recruitment strategies rely on implicit consent: the patient is automatically selected based upon his medical records (35). Case managers should be aware of the national legislation regarding patients’ rights when diagnosed with dementia. Personal data management also raises important ethical questions, especially when data transfer is involved.

CLINICAL TOOLS

Strengths and weaknesses of participants’ selection

Most studies explore CM intervention effectiveness in randomized controlled trials settings, which raises several limits: presence of selection biases, attrition, and endogeneity. In consequence, the generalizability of foreign results to the French context could be an issue. In many integrated models, enrolment rates are very low (26). Finally, generalizability of integrated care models results seems to be an issue, because of heterogeneity in evaluation methodology (43).

Strengths and weaknesses of standardized integrated care tools

Geriatric assessment technology tools are crucial to CM interventions success, as they allow the integration of medical and social services (37). Clinical tools provide real-time decision support for clinicians, and facilitate the creation of longitudinal datasets that can be used by researchers for “system planning, quality improvement and accountability” (64). The interRAI instruments, developed by an international research network, have been used in several settings to develop cost-effective home care management support systems (65) and improve staffs’ knowledge in care of frail elderly subjects (66). The interRAI tools have followed a standardization process: they use “a common language” and “refer to similar clinical concepts” (67). In Canada, the Outil Evaluation Multiclientele (OEMC) tools have been developed to “help case managers plan, monitor, and coordinate services” (3, 68). Each tool has a specific function: the Système de mesure de l’autonomie fonctionnelle (SMAF) has been developed and validated to assess patients’ disabilities (69) and classify them into Iso-SMAF profiles used to manage patients’ stays in care services (70). Finally, an Individualized
Service Plan tool has been created to help case managers assessing patients’ needs and plan professional services utilization (68).

The creation of large retrospective datasets that resulted from the use of these tools led to a more efficient approach of geriatric care (52, 71). The use of these clinical tools facilitated data transfer, case interpretation and training (72). These instruments have showed their reliability and efficacy in providing assessment and design care planning in mental health, aged care and disability services (52, 73, 74), which can be adapted to several countries and cultural contexts (75, 76). However, further research should be dedicated to the economical impact of their implementation. For instance, the interRAI-Home Care in New-Zealand was found to be associated with greater costs of prescribed preventive services than usual assessments (76).

New clinical areas to be explored

If some of current interventions can lead to small reductions in burden and depression, there is need to explore new clinical areas: 24-hour care, crisis intervention, coordination with primary care, and chronic disease management (32).

CONCLUSION

This short review shows the wide variety of systems, instruments, and interventions that can be used to implement the Fifth Measure of the French Alzheimer Plan. CM in Alzheimer’s disease can rely on the development of coordinated or fully integrated models. Case managers can use diverse clinical instrument to assess patients’ disabilities and evaluate their needs. Case managers’ tasks are multidimensional and involve collaborations with several other professions. In consequence, there is need for case managers with various background, skills, and training. The effectiveness of their actions can be evaluated using several outcomes measures: delay in institution, prevention of nursing home admission, use of professional care, reduction in informal caregivers’ burden.
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APPENDIX

MEASURE 5 OF THE FRENCH ALZHEIMER PLAN
http://www.plan-alzheimer.gouv.fr/

Alzheimer - Establishing "coordinators" throughout the country
The major difficulty lies in coordinating care professionals to support patients in their daily lives. The Plan thus proposes to create a coordinator. This single correspondent, responsible for the care provided as a whole, must be the direct point of contact for the patient and the primary-care doctor. His or her long-term mission, including any episodes in hospital, covers both the health and the social aspects, such as evaluating and elaborating an individual project, providing a link with the various care professionals and following up the actions taken.

Context
The complexity of Alzheimer’s disease, in which behavioral problems come together with sometimes dramatic social consequences and dependence, requires better coordination between health professionals and medico-social workers in order to offer patients and their families a tailored, effective care pathway.

Measure
A coordination role will be created on the basis of current "case management" trials, which will be completed in order to refine the tasks of coordinators, their training needs, profile and the number of people they are likely to handle. Managing the progress of dependent elderly people requires an ever-greater level of technical and organizational skill in carers. It also calls for more and more time spent on organization. The creation of a coordination role based on a professional function such as a nurse or a social worker is thus an emerging need, which will be dealt with in the Medico-Social Careers Plan.

The coordinator is a "conductor" of social and health care, providing the link between the teams and guaranteeing real multidisciplinary care suited to each individual’s situation. He or she operates as soon as the diagnosis is given, when the patient is referred to a specific centre by the memory unit, the CM2R or the primary-care doctor. He or she will then be responsible for producing a treatment and support plan and facilitating its implementation, providing his or her expertise to the patient and family in the health and social fields continuously, including times when the patient is hospitalised. He or she can be reached at the MAIA using the standard telephone number. He or she takes part in evaluating needs and planning services, provides liaison with care professionals, particularly the primary-care doctor, who has a crucial medical role in follow-up, and follows up the provision of the planned services.

The primary-care doctor is the guarantor of continuity of care for Alzheimer’s patients because he or she knows the person in their environment. The doctor, communicating with the patient and carers, is thus the coordinator’s direct contact for all aspects relating to healthcare. In addition, liaising with home help services, the coordinator monitors the quality of care at home; he or she helps carers by guiding them towards support structures and examining respite and temporary accommodation options with them to guard against crisis situations; he or she organises a more fluid transition between care at home and institutionalisation; liaising with the public authorities, the CCAS and the APA teams, he or she helps put together applications for social benefits; he or she provides guidance in seeking legal support (guardianship) etc.

In terms of initial training, these professionals may be nurses coordinating home care services, home help managers, CLIC staff or APA medical team members, social workers, members of health networks or independent nurses. Specific training will be put in place by 2009 as part of the Careers Plan. The coordinators will be employed by the MAIA. The trials in progress will be continued and completed in 2008, so that the training actions can be begun in 2009 and the objective of 1000 coordinators in MAIAs throughout the country can be achieved by 2012. This initial estimate of requirements will be refined and may be increased at a later date.
With an estimated total number of 850,000 cases over 75 years in France and 1 out of 5 deaths, Alzheimer’s disease and related disorders fully met objective criteria for health priorities. To go beyond statistics, over one hundred experts from all fields, managed by Professor Joël Ménard, an outstanding physician and scientist fully aware of public health challenges, met for 3 months at the end of 2007 to propose actions against this threat. Research was at the heart of their discussions.

Although less developed than for AIDS or Cancer, French research in Alzheimer’s disease and related disorders has specific strengths on which a powerful dynamic can be implemented:
- large structured groups conducting multidisciplinary research in the following areas: basic, clinical, epidemiological or social research;
- a dozen of researchers with international class scientific production;
- a network of memory clinics distributed all over the French territory;
- numerous international collaborations (Europe, Canada, Australia and the USA).

Following the report of these experts, the President of the French Republic, Nicolas Sarkozy, decided to launch, on February 1st 2008, a five years national plan on Alzheimer’s and related diseases (www.plan-alzheimer.gouv.fr) with three major keywords:

- improve the quality of life of patients and their families,
- understand to be able to act,
- mobilize for a societal challenge.

This second keyword is fully devoted to research and underlies specific orientations:

1. Reinforce the strengths;
2. Attract new teams;
3. Attract young researchers;
4. Reinforce the best clinical centres;
5. Increase interaction with pharmaceutical industries and biotech companies.
The implementation of this scientific policy is secured through a national network of excellence coordinated by the French National Foundation on Alzheimer’s disease and related disorders and a specific budget of 200 million euros.

Created in June 2008 by the French Ministry of Research to implement the research measures of the National Plan, this non-profitable private foundation, ensure an efficient and highly reactive programming of research in the field of Alzheimer’s disease and related disorders. The Board of Directors of the Foundation chaired by an outstanding international personality from the business world, Mr. Philippe Lagayette, associates with equal vote rights public institutions, private industries and qualified personalities from various fields (lay-group, research societies). The Foundation is assisted by an international Scientific Advisory Board chaired by Professor Joël Ménard and is managed by a general director, Professor Philippe Amouyel, assisted by administrative and scientific officers.

The Foundation launches calls for proposals according to the priorities identified and interconnects multiple other funding sources (ANR, PHRC, Inserm, CNRS, CNSA, Universities, European funds…). It also encourages public-private partnerships, reinforces productive teams and attracts new skills.

During the last year, two calls for proposals have been launched, one on experimental models and another one on human and social sciences. Several large structural projects have been founded, the follow-up of the large prospective study, the Three Cities study and a European GWAS collecting more than 20 000 samples including 6000 cases of Alzheimer’s disease. This last works allowed discovering two new genetic susceptibility factors for Alzheimer’s disease.

Finally, given the magnitude of the impact of Alzheimer’s diseases and related disorders an international mobilization of researchers was initiated by the Foundation, during the French Presidency of the European Union, through a new European pilot joint programming initiative gathering more than 20 countries, and a French-Canadian collaborative action with the ANR.

This large cooperation of researchers from all domains, from all countries and from both the academic and the private fields, is the only way to accelerate significantly the provision of solutions to fight efficiently these terrible diseases.

The National Plan focuses on 15 main objectives among which:

- constitution of genome wide association studies
- development of clinical research, evaluation of care options
- creation of doctorate and post-doctorate grants
- development of human and social sciences
- emergence of innovative approaches
- creation of a national centre for imaging
- physician training
- cohort tracking and information system
- public/private-sector partnerships
- European research area development...
## Composition of the Board of Directors

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