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When people live with multiple chronic diseases:
a collaborative approach to an emerging global challenge

JUNTA DE ANDALUCIA
Escuela Andaluza de Salud Pública
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Words cloud from chapter sections “Why is this topic important?” and “What do we know?”
[Available at: http://www.wordle.net]

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Published by ESCUELA ANDALUZA DE SALUD PÚBLICA

ISBN: 978-84-693-2470-7

DL: Gr-2653/2010

Printed in Granada: Alsur, S.C.A.

Layout and graphic design: Carmen F. Sigler. www.transversal.tv

How to reference
Jadad AR, Cabrera A, Martos F, Smith R, Lyons RF. When people live with multiple chronic diseases: a collaborative approach to an emerging global challenge. Granada: Andalusian School of Public Health; 2010. Available at: http://www.opimec.org/equipos/when-people-live-with-multiple-chronic-diseases/

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Chapter 4

Management models

This chapter is continuously evolving at www.opimec.org

Vignette: How it could be

The case management nurse at the health centre contacted the hospital doctor to update him on the evolution of an elderly patient, Mr. Smith. He had been discharged a week earlier, having been admitted to hospital as a result of an acute episode of his chronic cardiac failure, complicating his diabetes, hypertension and chronic renal failure. He was one of 3 patients with the same diagnosis being handled simultaneously by the nurse. Contact with the hospital doctor was essential for the medication adjustment her patients required to avoid further hospital admissions. There was no suitable clinical practice guideline for them, each suffering from multiple illnesses and having multiple needs. Since the heart failure management program for patients with multiple readmissions was started, the annual readmission rate had been brought down by 40% per year, with both patients and their families registering high levels of satisfaction. The case management nurse had played a key role in the program, from initial education of the patient in self-management to checking that treatment was being followed and handling home-help support in those cases where this was necessary. The whole system operated as a well orchestrated unit, thanks to an advanced information and communication infrastructure that not only enabled seamless interactions between the hospital and ambulatory care, but also took into account the preferences and values of carers and relatives in the community. This had thus released resources at the hospital, allowing greater capacity to deal with the new pandemic flu outbreak.

The education program for patients with low-risk heart failure had been equally successful. These patients, who did not generally suffer any major disability, met in the health centre on a periodic basis for preventive education on vascular risk factors and lifestyles. Nicotine addiction workshops had also been organized. In accordance with their specific profile, each patient had a series of individual sessions, while patients with shared problems were encouraged to form into groups. One group of *patients with heart failure had, with the support of the local authority, managed to secure a space at the municipal sports hall for cardiac rehabilitation, supervised by doctors who were provided with information about each patient involved in the program.*

Summary

The response to the needs of people living with multiple chronic illnesses represents one of the main challenges for health care systems in the 21st century.

Progress in this area demands a transformation of current conceptual frameworks to place individuals, their environment and their health-related needs at the core of the health system, rather than the illness or the needs of managers, clinicians or policy makers.

This chapter discusses the most prominent models to improve the health of those living with two or more chronic conditions. The adoption of such models, however, requires local adaptation, leadership and change management strategies to overcome the many existing obstacles that exist in most health systems.

Models for the management of people living with chronic diseases are in their relative infancy. Wagner's *Chronic Care Model* (CCM), the first broadly disseminated system and the basis for subsequent approaches, has been in place for scarcely 20 years. Newer models, such as the *Expanded Chronic Care Model* employed and proposed by the government of British Columbia in Canada, and the World Health Organization (WHO)'s *Innovative Care for Chronic Conditions Framework are* in general variants on that original model, emphasizing the importance of community engagement, prevention and health promotion activities, and the need to optimize the use of resources and the formulation of health policies.

The creation of valid models for patients living with multiple chronic conditions (complex cases), who consume a disproportionately high volume of resources, remains an unmet challenge, as the focus of all existing models and most of the solid evidence and experience available relate to specific individual conditions. This is compounded by the lack of clinical practice guidelines and the limited applicability of standards for individual illnesses to cases in which multiple conditions co-exist.

There are other approaches that could be used to improve the management of people living with multiple chronic diseases. Kaiser Permanente's pyramid-based stratification

model could facilitate triage of patients to three levels of intervention according to the level of complexity. Patients at the top of the pyramid represent only 3-5% of cases, but are the most complex and consume the highest share of resources. Therefore, these patients are assigned to comprehensive care plans designed to reduce unnecessary use of specialist resources and, particularly, to avoid hospital admissions. This has inspired successful additional approaches such as the Guided Care Model, where trained nursing staff in coordination with a medical team take care of the assessment, planning, care and monitoring of complex chronic cases identified by means of predictive modeling.

Although considerable progress has been made in terms of management models over the last two decades, we still have much to learn as to their application to populations of individuals with multiple conditions, in particular in heterogeneous socioeconomic and ethno-cultural contexts, and their impact on health system resources.

Why is this topic important?

Improved knowledge of the life cycle of chronic diseases and of the interactions among multiple diseases, at least in theory, should lead to the development of effective management models. A model, however, is not a recipe book, but rather a multidimensional framework to guide initiatives designed to handle a complex problem.

It is hoped that models specifically designed to improve the management of multiple chronic diseases will help curb the exponential increase in costs associated with them by shifting emphasis away from acute care; by giving patients, caregivers and the community a leading role as agents of change; by diversifying functions for health professionals; by optimizing care processes and the use of new technologies; and by expanding the scope of services beyond the limits of the current health care system.

In both high- and low-income countries, models could help shift health systems from health services that are reactive, fragmented and focused on specialist care, towards more proactive, coordinated, community-based interventions.

Care models also promise to help improve the implementation and dissemination of effective interventions for chronic disease management (1, 2), overcoming many cultural, institutional, professional and sociopolitical barriers (3-5).

This chapter focuses on comprehensive «health management» models that could lead to an integrated response that matches the complexity of the challenges created by multiple chronic diseases (6, 7).

What do we know?

Generic chronic disease management models

The most prominent approach is the Chronic Care Model (CCM) developed by Ed Wagner and associates at the MacColl Institute for Healthcare Innovation in Seattle, USA (8, 9).

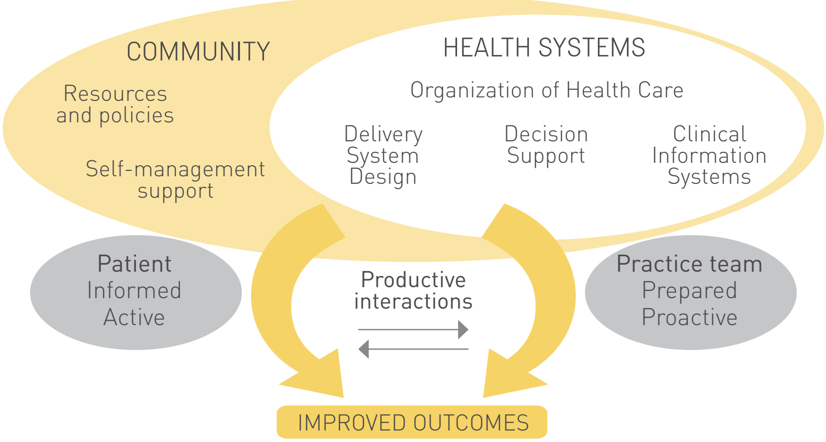
This model resulted from a number of efforts to improve the management of chronic conditions within integrated provider systems such as the Group Health Cooperative and Lovelace Health System in the USA. The development of this model was guided by systematic reviews of the literature and input from a national panel of experts, and emphasized the importance of rethinking and redesigning clinical practice at the community level.

The CCM acknowledges that chronic disease management results from the interactions of three overlapping areas: 1) the community as a whole, with its policies and multiple public and private resources; 2) the health system, with its provider organizations and insurance systems; and 3) clinical practice. Within this framework, the CCM identifies essential, interdependent elements (Figure 1) that must interact effectively and efficiently to achieve optimum care of patients with chronic disease (Figure 1). The ultimate purpose of the model is to position an active and informed patient at the centre of a system that includes a proactive team of professionals with the necessary skills and expertise. The result should be high-quality care, high levels of satisfaction and improved outcomes (10, 11).

Various models have used CCM as the basis for subsequent expansions or adaptations. A case in point is the Expanded Chronic Care Model (12) of the government of British Columbia in Canada (see Figure 2), which stresses the community context as well as the importance of prevention and health promotion.

Figure 1

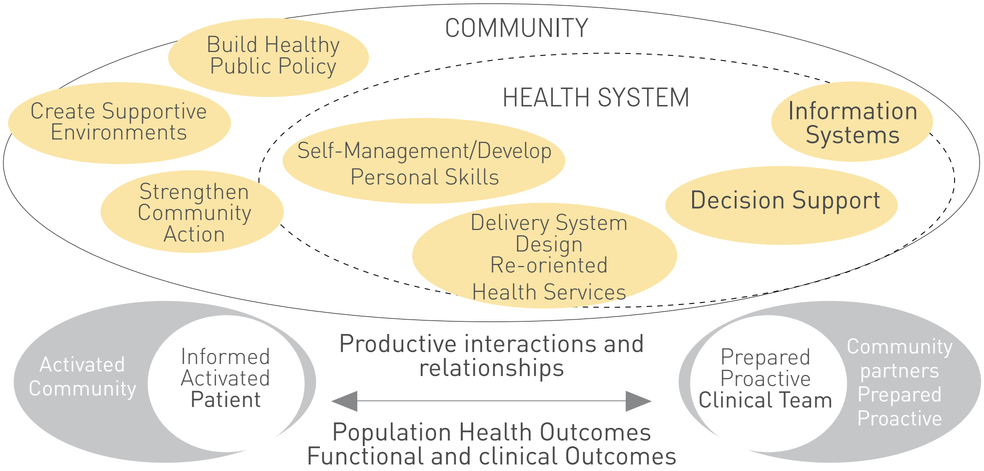
The Chronic Care Model



Source: *Developed by The Mac Coll Institute for Healthcare Innovation, ACP-ASIM Journal and Books.*

Figure 2

The Expanded Chronic Care Model



Source: *Ministry of Health: Government of British Columbia. Expanded Chronic Care Model.*

Another popular adaptation of the CCM is the WHO's Innovative Care for Chronic Conditions (ICCC) Framework (2, 13) model (Figure 3), which adds a health policy perspective. One of its key aspects is the emphasis it places on the need to optimize the use of available health resources within a particular geographical and population context. Such a focus is crucial in many mid- and low-income countries where multiple provider infrastructures coexist, with evident overlaps and sub-optimal use of services. Table 1 presents a summary of the key ideas underpinning this model.

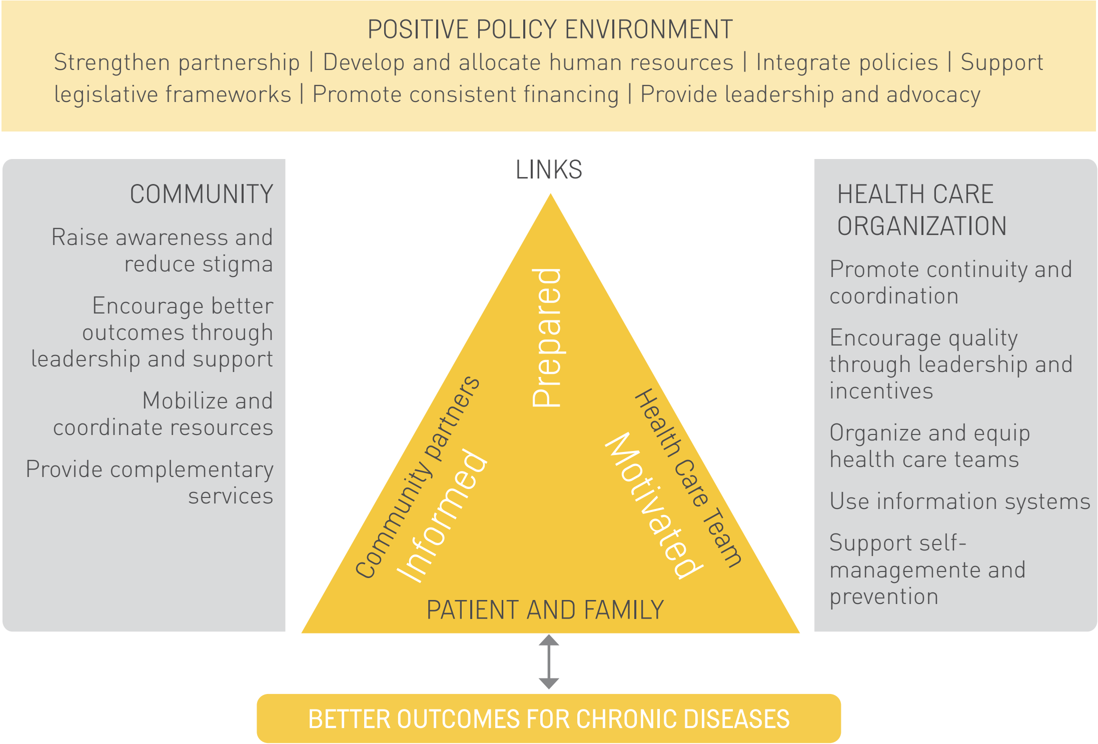
Table 1

Key elements of the ICCC model

KEY ELEMENTS OF THE ICCC MODEL
Evidence-based decision-making
Population health focus
Focus on prevention
Emphasis on quality of care and systemic quality
Flexibility/adaptability
Integration as the hard and fractal core of the model

Figure 3

WHO, Innovative Care for Chronic Conditions Framework, 2002



Source: *WHO. Innovative Care for Chronic Conditions: Building Blocks for Action. 2002.*

The ICCC makes key complementary contributions to the CCM(14):

- At the macro-level, it emphasizes the need for a positive political environment to support the reorientation of services towards the needs of people living with chronic conditions. Solid leadership, inter-sectoral action and partnerships, policy integration, financial sustainability, and the provision and development of qualified human resources represent key elements and constitute a dimension not explicitly dealt with in Wagner's original version of the CCM.

- At the meso-level, the emphasis remains on the role of community actors and the importance of service integration and coordination. Meanwhile, issues related to decision support are included under resource provision, to match needs in contexts where there is a lack of equipment and medication.
- At the micro-level, the dyad established within the CCM between healthcare professional and patient is extended to a triad that now involves the community. The term «activated» in reference to patients is replaced by «motivated and prepared».

There exists a broad consensus about the potential value of the ICCC in low-income countries (15), despite the fact that the evidence which supports model-driven transformational initiatives is very substantially drawn from experiences in high-income countries and from within the conceptual framework of the CCM. The following are a few highlights of such evidence:

- Studies supported through the Institute for Healthcare's Improving Chronic Illness Care program (16) illustrate that external guidance and the involvement of multi-disciplinary teams from a wide range of clinical contexts are essential for successful implementation of the model. Nonetheless, contextual factors may limit the success and sustainability of the changes, with the most successful experiences being provided by large, well-resourced teams. Further research is needed as to the critical factors for success and the cultural, organizational, professional and resource-based barriers which influence the practical implementation of the CCM (17, 18).
- The presence of one or more of the components of the CCM leads to improved clinical outcomes and to more effective care processes, with most evidence gathered during the management of diabetes, heart failure, asthma and depression (11). Extrapolating results from the application of the model to the management of diabetes at a population level, one might expect a reduction of mortality of more than 10% (19). All the components of the model, except for community support (for which there is a dearth of research), have been associated with clinical and process improvements. The two single most effective components seem to be the redesign of clinical practice and support for self-management (20, 21). Although it would be challenging to evaluate the entire CCM as an integrated, multi-component intervention, it has been shown that a greater alignment of primary care with CCM bears a positive relationship with improved process and clinical indicators (22, 23).

- Although the philosophy of an integrated, multi-faceted approach is integral to the CCM, it need not imply that every possible type of intervention is equally effective. It is still valuable to ask which components are necessary, sufficient, or most important to a multi-faceted strategy. This is a particularly important question for organizations that may be unable to implement all of the model's components simultaneously, and need guidance on which interventions to introduce first, next, or (perhaps) not at all. Some interventions, for example delivery system redesign, may have positive effects all by themselves, whereas others, for example clinical information systems, may be beneficial only when used to support and facilitate other interventions.
- The initial studies by Parchman et al. avoided differentiating between the effects of different components of the CCM, but two more recent studies by Parchman and Kaissi did differentiate among components. These studies found that different CCM components were correlated with different outcomes (HbA1C control and self-management behavior), and clinical information systems were inversely related to both of these desirable outcomes. Since these studies were cross-sectional, they do not lend themselves to firm conclusions, but they do point to the continuing relevance of research assessing the contributions of specific elements of the CCM (both separately and in various combinations) (24, 25).
- Although studies of the economic impact of the CCM are limited, cost savings and cost-effectiveness have been reported for diabetic patients (26-28).

CCM and complex chronic cases

Although the holistic and integrated focus of the CCM matches the reality of complex chronic diseases, there is very little evidence on its applicability and effectiveness in this area (6, 29).

This is compounded by the absence of clinical practice guidelines addressing multiple conditions or that are designed to enable primary care professionals to consider the individual circumstances and preferences of people who live with multiple chronic diseases (30).

In addition, there is a need for quality standards for services targeting patients with multiple chronic conditions, particularly in relation to the coordination of care, patient and carer education, empowerment in support of self-management and shared decisions, while taking into consideration individual preferences and circumstances.

At the root of the existing knowledge gaps is the fact that patients with poly-pathology are often excluded from clinical trials (31). In the words of Upshur, what is good for the disease may not be good for the patient (32).

Against this background, it is not surprising that the reality of complex chronic patients has played a decisive role in the development of another highly significant adaptation of the CCM: The Guided Care Model. Under this model, primary care nurses, in coordination with a medical team, take care of the evaluation, planning, care and follow-up of complex chronic patients identified by means of predictive modeling. Preliminary evidence from a cluster randomized controlled trial suggests that this approach leads to improvement in health outcomes, reduced costs, a lower burden on carers and the family, and greater levels of satisfaction among health professionals (33-36).

Stratification of risks and case management

Risk stratification means the classification of individuals into categories in accordance with their probability of suffering deterioration in their health.

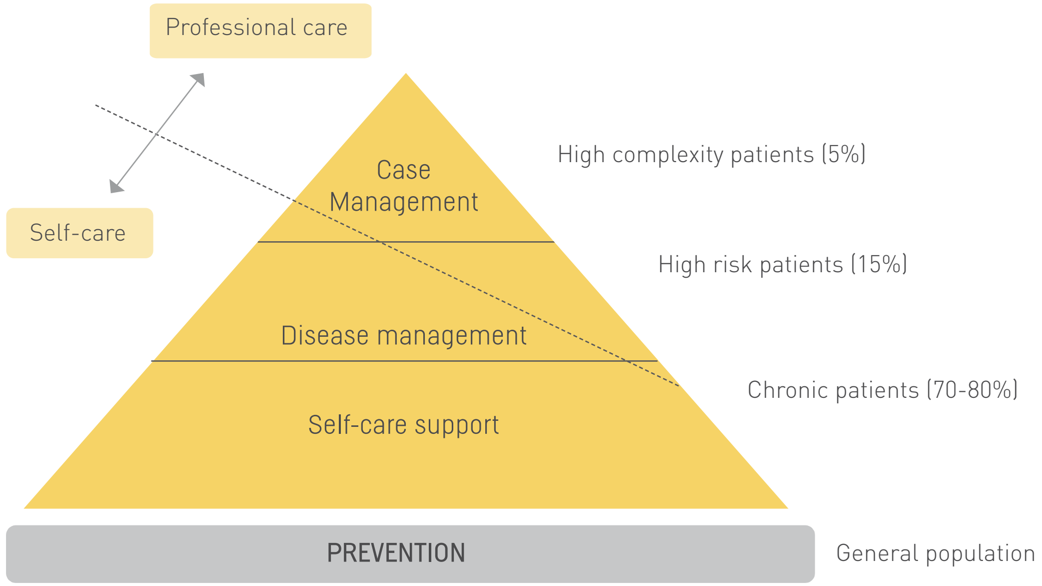
The most widely used approach to stratification is known as the Kaiser Pyramid (Figure 4), developed by Kaiser Permanente in the United States to categorize patients into three levels of intervention depending on their level of complexity. At the bottom of the pyramid, Kaiser places healthy members of the public for whom prevention and early diagnosis of disease are the priorities. At the second level, where patients have some form of chronic illness, the emphasis shifts to self-management, the appropriate administration of medication and health education. At the third level, patients identified as complex (3% to 5% of the total) are assigned care plans guided by case management efforts designed to reduce inappropriate use of specialist services and to avoid hospital admissions.

Some European public health systems, notably the NHS (National Health Service) in Britain, have tried applying the Kaiser model in their contexts (37-39).

The method used to identify patients with complex diseases varies from model to model. The NHS tried adapting the US Evercare model (see details below) but because of the unavailability of data had to identify patients using eligibility criteria (40). Others subsequently followed predictive modeling (41) using a wide range of methods such as Adjusted Clinical Groups-Predictive Modeling (ACGs-PM), Diagnostic Cost Groups (DCGs), Patients at Risk of Re-Hospitalization (PARR 1 and 2) and the Combined Predictive Model (CPM) (42).

Figure 4

Kaiser Permanent risk stratification pyramid



Regardless of the approach, the initial step is the collection and analysis of demographic, clinical or cost databases to establish, for a given individual or group of individuals, the risk of suffering a specific illness or an event associated with deterioration in their health (43).

The event most frequently measured is unscheduled hospital admission, although many others may be employed, such as emergency room visits, drug costs and loss of independence. Stratification can also be performed on the basis of the different prevalence among different populations of risk factors based on unhealthy lifestyles (44).

The risk stratification technique arose for economic reasons, as insurance companies started to use it to create different products or premiums according to the risk profile of their clients, while avoiding the introduction of models that reject individuals based on previous conditions. In national health systems, risk adjustment and stratification allows for the differential allocation of health services and activities (preventive, corrective or compensatory) and resources, aiming to avoid critical system overload. In short, risk stratification models enable the identification and management of individuals who require the most intensive actions, such as elderly patients with multiple complex conditions. In these cases in particular, stratification seeks to avoid unscheduled hospital admissions (45), to optimize resource allocation (46), to promote patient self-management (47), to prioritize the intensity of interventions in all settings (48) and can even be used for the selection of participants in clinical trials (49).

Although the increasingly widespread application of electronic health records is facilitating risk stratification, the availability of precise information with low rates of data loss is still difficult to achieve in most settings. In many cases, resources must be invested in data transformation for analytical purposes. In others, the classification of illnesses is a common and major source of distortion. Misclassification, for instance, has been described in up to 30% of patients using the International Classification of Diseases (ICD) codes (50).

There are problems arising from the complex condition itself. Co-morbidity is generally assessed using scales that in some way add up the number of illnesses suffered by an individual, with weighting based on severity, such as the Charlson Index (51) (Chapter 3). Some groups have proposed the selection of complex patient groups by means of associations of specific illnesses (52) although others claim that specific disease combinations are of lesser relevance than the burden of co-morbidity (53).

Stratification by frailty or illness has also proved useful during natural disasters, such as Hurricane Katrina in New Orleans. Although evacuation strategies stratified by level of economic income were applied, the elderly or chronically ill within each social stratum had fewer options for evacuation than healthy people (54).

Stratification is also fueling the increasing interest in case management, a concept that has its origins in the care of non-institutionalized psychiatric cases in the USA during the 1950s. Case management is a complex intervention, generally led by nursing staff, which covers a wide range of interventions including patient identification, the evaluation of problems and needs, planning of care in accordance with such needs, coordination of services, and review, monitoring and adaptation of the care plan. Case management is usually promoted either as a key component or as a complement to other elements within multi-component approaches (55-57).

Evercare is the cornerstone of one of the most widespread care coordination programs in the United States, with more than 100,000 individuals currently signed up across 35 states (58). Its basic principles are:

- Individual whole-person approach to elderly care is essential, to promote the highest level of independence, well-being and quality of life, and to avoid adverse effects from medication (with the emphasis on poly-pharmacy).
- The principal provider is the primary care system. The best placed professional to implement the plan is a community-based nurse acting as clinical agent, partner, patient educator, coordinator and counselor. Only a third of work time is dedicated to direct patient care (59).
- Care is provided in the least invasive manner and context.
- Decisions are supported by data recorded using advanced technological platforms.

The first step in the model is identification of high-risk elderly patients, for whom an individual care plan is devised. Advanced primary nurses are then allocated a list of patients whom they regularly supervise. They are responsible for providing additional care, including admissions to nursing homes or hospitals.

Under the Evercare model, nurses direct and provide care, with the emphasis on psychosocial well-being. Participating physicians must have experience and skills in geriatrics, in particular in the care of frail individuals. Transfer of care is minimized, and the proportion of care received at nursing homes increased. Early detection and surveillance programs are applied, with teams acting as the patient's representatives, in an attempt to obtain the maximum benefit in care from their medical insurance. The family is involved in patient care, with intense and consistent communication among family, professional team and nursing staff.

An evaluation of the system has demonstrated reductions of 50% in hospital admissions rates, without an increase in mortality, with cost savings and high levels of satisfaction (60).

In light of this success in the USA, in 2003 the British Department of Health decided to pilot an implementation of the Evercare model at 9 Primary Care Trusts (61). A preliminary analysis identified a high-risk population including individuals with two or more hospital admissions over the past year. This group represented 3% of the population aged over 65, but accounted for 35% of unscheduled admissions for that age band. Surprisingly, many of these patients were not actively being dealt with by the system: only 24% were registered as cases by the district nurses, and only one third were known to social services. Curiously, 75% of the highest-risk population lived in the community, and only 6% and 10% in residential homes and nursing homes respectively. The use of an adapted version of Evercare with a community focus in the NHS, and the differences between the healthcare contexts in the US and the United Kingdom, may have led to what seemed to be very different results. A formal evaluation through pilot experiments did not show a reduction in urgent hospital admissions, average hospital stays and mortality (62). The evaluation did, however, have many problems (63), and the seeming «failure» of the Evercare program in England may have been simply because there was no time to implement the program fully (it took several years in the US to achieve reduced hospital admissions) or because the means of selecting patients was inadequate. Despite the failures the NHS has persisted with case management of the frail elderly with complex chronic disease. This may be partly because qualitative evaluation by the same independent group who did the quantitative study showed that patients and carers liked the program very much, as did the nurses and doctors involved (64).

What do we need to know?

Although there is growing evidence of the effectiveness and efficiency of interventions related to chronic care management (7, 11, 14, 65-72) (Table 2), there is little specifically related to the impact of care models for the management of different combinations of complex diseases.

Some disappointing results from the application of the Evercare model in the British NHS, along with somewhat promising new evidence in support of case management of vulnerable elderly people (70, 74-76) underscore the need for further efforts to understand the role of care models for the management of multiple chronic diseases (77). Such efforts should focus on:

- The applicability and impact of different models in diverse contexts.
- The development of a consistent language for the different elements in the models.
- Standardization of interventions.
- Comparative evaluation of the benefits of multiple vs. isolated interventions.

- Implementation strategies to facilitate rapid and successful implementation and dissemination.
- Their economic impact and efficiency.

Table 2

Effective interventions in the management of chronic patients (produced by the authors) (7, 11, 14, 65-72)

KEY ELEMENTS OF THE ICCC MODEL
Integrated disease management models and programs (of the CCM type)
Disease management programs for specific conditions: diabetes, heart failure, etc.
Service coordination and integration initiatives
Strengthening of primary care
Support and promotion of self-management
Geriatric evaluation
Identification of groups at higher risk of hospitalization
Early discharge programs for specific illnesses
Expansion of nursing roles
Remote monitoring
Multidisciplinary interventions

What innovative strategies could fill the gaps?

Views on innovation in chronic disease management models vary between two extremes, from the most optimistic forecasts as to their impact (78) (reduction in mortality and resource utilization, with net savings to the system) to the more skeptical, questioning whether they are worthwhile (79).

As noted above, there is evidence supporting mostly the effectiveness and efficiency of individual interventions (80-87), but there is still a lack of standardization in almost all aspects of such interventions. Some prestigious organizations have proposed the use of a standard taxonomy (88), and there are projects aiming to enrich this with the emphasis on multiple conditions (89).

Cooperation, especially across institutional, national and cultural boundaries, is essential to avoid overlapping efforts, to encourage a public debate, and to promote effective policy change. New technologies could play an important role, not only to facilitate meetings and communication across long distances, but also to promote the design and implementation of multi-centric studies using standardized measurements.

Although the context for transformative efforts is highly favorable, bringing about large scale shifts in the health system to meet the challenges posed by complex chronic diseases will demand planning, change management and concerted efforts at all levels within the health system.

For any meaningful change to occur, policy makers, funders and health care managers would need to view the sector with new eyes and understand that the playing field now involves complex adaptive systems that have rendered traditional solutions irrelevant. Health professionals and patients cannot be considered any longer as «standardizable» and predictable components of a depersonalized system.

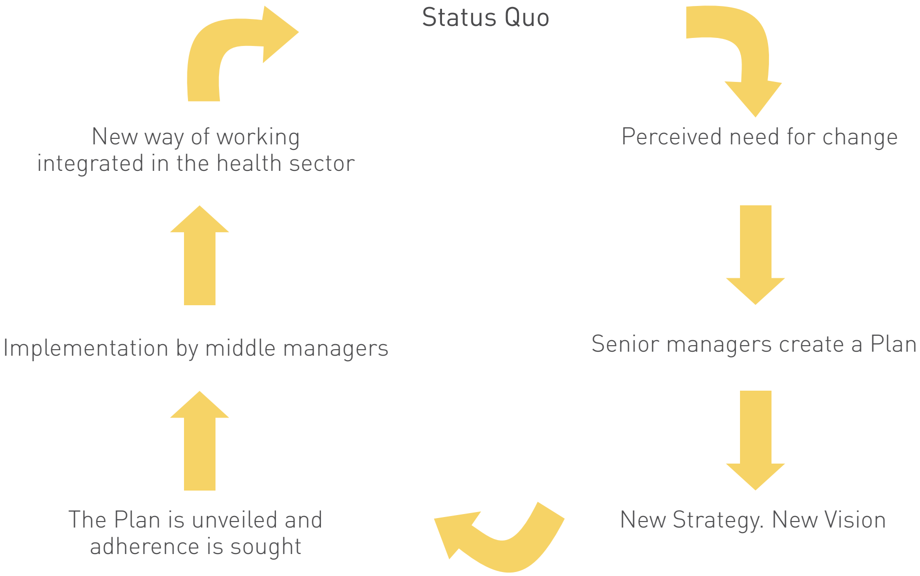
The complexity of the desired system change can be better illustrated by means of an example. Studies indicate that 76% of hospital readmissions are avoidable (90) within 30 days of discharge. This represents 13% of admissions to a modern-day hospital, a high proportion of which are complex chronic «frequent flyer» patients (Chapter 3).

The evidence indicates that this situation could be rectified through a reduction in complication rates during hospital stays, improvement of communication in the hospital discharge process, closer monitoring and active participation of the patients at home, and better communication and cooperation between hospital and primary care following discharge. These outcomes could be achieved by means of optimal continuity of care resulting from integrated care processes that guarantee that patients remain engaged and monitored following discharge, and that managers and professionals work seamlessly across the hospital-community divide (Chapter 6). Unfortunately, most systems around the world continue to operate under highly centralized policies and procedures that nurture a traditional acute care model in which hospitals rule over a fragmented ecosystem of services.

With the impending pandemic of chronic diseases, and with the new challenges created by complex cases, it is imperative to muster the levels of leadership and commitment to change, and to abandon the usual linear process of planned change that pervades most systems (Figure 5).

Figure 5

The linear process of planned change



Adapted from «Planned Change» (91).

Times have changed. This highly prevalent planning approach reflects an excessively simplistic vision of the way organizations work today. Although it is applied with the best of intentions in an attempt to reorganize the sector on the basis of hierarchy and linear top-down planning, it is outdated, as it reflects the conditions of an era of management derived from the industrial age, with central managers at an organization defining strategy, creating structures and systems to influence what have been called «organization men» (92).

It is a philosophy that expected a high degree of conformism from its human resources, and this has for some time not corresponded to the situation in the health sector, where health professionals and local administrators are increasingly alienated and disconnected from the central management and policy-making engines of the system.

Nowadays, change will only be possible through local leadership and enthusiastic participation of health professionals, administrators and the public within the network of care. This calls also for greater sophistication in the management/planning of the system to enable professionals and users to play a much more strategic role in the development and refinement of models that match the needs of people living with multiple chronic diseases. This is clearly a complex cultural change for which there is no magic wand.

As with any other complex system, progressive steps will be needed to re-build the system from the bottom up, while drawing on the intellectual capital of front line professionals, administrators, patients and their loved ones. In fact, it has been shown that the most substantial and sustained changes have occurred at those organizations which allow for bottom-up change instigated by frontline users, professionals and managers (93).

As suggested above, policy-makers must devote greater efforts to enabling those working in different parts of the organization (primary and hospital care in particular) to create new ways of working together and to generate communities of practice that spur organizational change. The idea is to promote entrepreneurship among professionals and local administrators rather than expecting them to implement the scripts designed by those «high up».

This more decentralized form of leadership does not mean sacrificing the benefits achieved over recent years through direct, centralized management. Nor does it mean a return to the past, to a system in which professionals are not accountable and do not need to report back. In a decentralized system, central policy-makers and managers should act and be perceived as motivators, promoters of interrelationships at all levels and network facilitators. One of their main roles in a modern system should be the reinforcement of incentives to encourage local teams of health professionals, administrators and members of the public to experiment with improvements of their own device, facilitating the availability of resources, analyzing and comparing results and disseminating lessons learnt across other teams within the network.

Another key role for central policy makers and managers could be the creation of mechanisms to support management training and the promotion of local leadership. Local managers need to know, among other aspects, how to motivate teams, build networks, involve the community in change management, and harmonize local initiatives with the general strategies pursued by the organization at large. In the Basque Country (Spain), for example, an organization has been created to fulfill this role. This organization, known as O+Berri, has as one of its main functions the promotion of best practice communities throughout the organization. In this regard, the agency also promotes connectivity among different best practice communities, while assisting sector managers in analyzing trends to optimize their strategies for the dissemination of innovations and policies throughout the system.

The strength of this more decentralized form of leadership and administration lies in taking advantage of the intellectual capacity of the network and abandoning the false illusion that it is possible to devise one single operational model for an entire region or country. Within such a system, the differences that exist across organizations should be viewed as a strength, not as a weakness, with leaders at all levels relentlessly pursuing innovative ways to facilitate and enable improvements in contexts that are more receptive to such changes thanks to their collective effort and commitment.

In addition, we need greater investment and an active quest for new ideas to be incorporated within the models, with bolder forms of evaluation allowing for a sharper learning curve (the clinical trial model is perfect in isolating simple effects, but it is of less use in learning from complex experiences). The new forms should include participatory evaluation taking into consideration the perspectives and expectations of professionals and users. In complex contexts qualitative research techniques may clear the path more effectively than quantitative techniques, which will always be subject to bias in omitting significant aspects for which data are not available.

What is needed is a pioneering spirit in order to go beyond the existing models. Perhaps more radical change is needed (in the sense of dealing with the root) in cultural forms of dealing with the responsibility of individuals as to their health and illness. What is lacking is a clear commitment to the capacity of individuals to acquire knowledge, to change their conduct and allow them to choose freely.

Contributors
Rafael Bengoa, Francisco Martos and Roberto Nuño wrote the first draft of this chapter in Spanish and approved its English translation. Alejandro Jadad revised the English translation extensively and approved it before its release for external contributions through the OPIMEC platform in both languages. Sara Kreindler, Tracy Novack and Rafael Pinilla made important contributions, which Richard Smith incorporated into a revised version of the chapter, which was approved by the other contributors. Alejandro Jadad made the final revisions and approved the version that was included in the paper-based book.

Acknowledgments
Francisca Domínguez Guerrero y Rodrigo Gutiérrez made insightful comments to the chapter that did not lead to changes to its contents.

How to reference
Bengoa R*, Martos F*, Nuño R*, Kreindler S, Novack T, Pinilla R. [*Main contributors] Management models. In: Jadad AR, Cabrera A, Martos F, Smith R, Lyons RF. When people live with multiple chronic diseases: a collaborative approach to an emerging global challenge. Granada: Andalusian School of Public Health; 2010. Available at: http://www.opimec.org/equipos/when-people-live-with-multiple-chronic-diseases/

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Abbreviations

AAL: Ambient Assisted Living

BMJ: British Medical Journal

CAM: Complementary And Alternative Medicine

CCD: Complex Chronic Disease

CCM: Chronic Care Model

CIRS: Chronic Illness Resources Survey

CMPs: Case Management Programs

CVD: Cardiovascular Disease

DMPs: Disease Management Programs

EASP: *Escuela Andaluza de Salud Pública*

EPP CIC: Expert Patients Programme Community Interest Company

GRIN: Genomics, Robotics, Informatics and Nanotechnologies

ICCC: Innovative Care for Chronic Conditions

ICD: International Classification of Diseases

ICED: Index of Coexisting Disease

IDS: Individual Disease Severity

MCCs: Multiple Chronic Conditions

MD team: Medical Doctor

MeSH: Medicines Medical Subject Headings

MI: Motivational interviewing

MPOWER: Monitor (tobacco use and prevention policies), Protect (people from tobacco smoke), Offer (help to quit tobacco use), Warn (about the dangers of tobacco), Enforce (bans on tobacco advertising, promotion and sponsorship), Raise (taxes on tobacco)

NHIS: National Health Interview Survey

NHS: National Health Service

OECD: Organization for Economic Co-operation and Development

OPIMEC: *Observatorio de Prácticas Innovadoras en el Manejo de Enfermedades Crónicas Complejas*

PACE: Program of All-inclusive Care

QALY: Quality-Adjusted Life Year

QRISK: Cardiovascular disease risk score

RE-AIM: Reach, Effectiveness, Adoption, Implementation and Maintenance

SNOMED CT: Systematized Nomenclature of Medicine-Clinical Terms

SSPA: *Sistema Sanitario Público de Andalucía*

TCAM: Traditional Complementary And Alternative Medicine

TPE: Therapeutic patient education

VHA: Veterans Health Administration

WHO: World Health Organization

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[Available at: http://www.wordle.net]

-Contents-

When people live with multiple chronic diseases:

a collaborative approach to an emerging global challenge

This book is continuously evolving at www.opimec.org

Diseño:www.transversal.tv

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Observatory of Innovative Practices for Complex Chronic Diseases Management

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