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



Escuela Andaluza de Salud Pública  
CONSEJERÍA DE SALUD







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

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## Primary care, institutional services and integrated management processes

This chapter is continuously evolving at [www.opimec.org](http://www.opimec.org)

### Vignette: How it could be

*«What are you laughing about, Dad? How can you leave the hospital laughing? Have you been playing tricks again?». Manuel had been a doctor, but he preferred to keep it quiet. He said he would rather go incognito to keep tabs on «his system». At 85 years of age he felt he had helped shape the world around him and had a sense of pride in that. He had been a fighter his entire life. After spending his teenage years promoting social justice, he had belonged to the «generation of change» that really drove forward the National Health System in his country, creating the specialty of Family and Community Medicine. In 2005, after seeing the writing on the wall, he was one of the champions of healthcare service integration. In 2022, after he had retired and fallen ill, he began to play an active role in the associations, committees and networks, which he helped create through his local primary care centre.*

*Now his diabetes mellitus and high blood pressure had ended up taking their toll, and leading to cardiac and renal failure. More recently, he had been diagnosed as having prostate cancer, which fortunately was growing slowly. He nonetheless maintained his independence. He did not want to be a burden on his family, and had chosen to continue living in his local neighborhood. Over recent years he had become one of the real leaders and role models of his community. He played an active role in self-help groups, working with Eva, his nurse, and among the virtual social networks his contributions had become highly valued by other patients and health professionals.*

*Over the past few years his situation had gradually worsened, especially after he broke his hip. That offered a real opportunity for him to put the system to the test. During his time in hospital he noted that the internist turned up on the first day, and that she was familiar with his case already, thanks to the powerful global clinical information system available to her. As soon as they began planning*

*his discharge, Eva got in touch with the specialist and Manuel, and together they decided it would be better for him to spend a few days at a residential facility to begin his rehabilitation. Julia, his daughter, wanted to take him home with her, but he chose to spend two weeks at such a facility and then go back home, where he would receive assistance which Eva had arranged via the local primary care centre. When he returned to his home, the physiotherapist was there waiting for him, along with support staff who would help him keep the house in order and so maintain his independence. And his partners from the primary care centre were there every day, online and often in person, also assisting him. All these forms of support just fell into place. They all knew his history and his aims. No one asked him for his credit card.*

*This was society repaying him a part of what he had contributed throughout his life, both professionally and as a taxpayer. The system worked, as was illustrated during a recent visit to a local pharmacy. He had gone out for a walk, when his hip pain became unbearable. When he asked a pharmacist for an anti-inflammatory painkiller, an electronic alert reminded them about his kidney problems. Something similar happened when he had to seek support for dehydration during the end-of-year holidays. At the small emergency room facility by the beach where he spent so many wonderful moments with his grandchildren they knew about his renal problems and, having been alerted, gave him a personalized program.*

*Over the past year his chronic heart failure had been the major cause for concern, and on two occasions his family practitioner, Mario, had advised that he go into hospital. While he was there, he noticed that the hospital internist had spoken with Mario and had planned the three days he would be admitted step-by-step. During his most recent pneumonia attack everything went like clockwork. Mario linked him to the remote monitoring system, which allowed him to stay home while ensuring his safety. From the hospital and the primary care centre his progress was monitored closely. He could even hold a four-way conference with Paula, Mario and Eva. His daughter, Julia, would be able to carry on working and help out her father from her own home or office. Yes, Manuel was satisfied, because he knew all this was not because he had been a physician, but because in his «system» it was a top priority to support his fight to keep him alive and well.*

## Summary

- Health systems are not keeping pace with the rapid changes in disease patterns that are occurring in most societies around the world. Most countries continue to structure their health systems into different levels that distinguish between health and social services, and that separate primary care from specialized care, creating serious challenges for the management of polypathology.



- Those organizations that recognize that traditional models of care are not only outdated but harmful are embarking on aggressive efforts to create new clinical roles, workflows and processes with which to meet the complex needs of people living with multiple chronic diseases.
- Successful programs for these patients emphasize the role of primary care as central during the coordination of health and social services, and the importance of process re-engineering to align the skills and motivations of different stakeholders in different settings.
- The partnership of physicians and nurses working in the community with hospital-based general internists and nurses, guided by risk-based stratification methods and comprehensive care processes, promises to be an effective way to strengthen the continuity and personalization of health and social services for people living with multiple chronic diseases.

## Why is this topic important?

Traditional approaches to organizing and providing health services do not match the needs of people living with multiple chronic diseases (1, 2). Rather than dealing with episodes of care within a system that continues to focus on acute conditions, with a separation between primary and specialized care, and a gap between health and social services (3), we all need a system that follows a comprehensive and integrated approach to services provided by teams that transcend institutional boundaries (4), away from conventional performance indicators that reinforce fragmentation of care (5).

Developing and nurturing services that meet the needs of the increasing number of people living with multiple chronic diseases becomes even more relevant as the population ages and becomes frailer (6-12). As multiple chronic illnesses accumulate and individuals become progressively more fragile, sliding even further down the slippery slope of dependency (13, 14), they need a comprehensive response from social and health services, in a timely and personalized fashion (15). Nonetheless, even in settings with sophisticated networks of social services there is often poor integration with the health system proper (16). It is reassuring, on the other hand, to witness how the integration of social and health services is viewed increasingly as a major priority in Canada, Denmark, the Netherlands, the United Kingdom and Spain (17-19). There seems to be some degree of agreement within this context as to the need to restructure

care organizations (20) as reflected by the numerous care integration projects which have arisen over recent years (21). Common elements across such projects are not only clinical services that follow a people-centered approach, but also efforts to harmonize financial and organizational structures, with coordinated and well aligned incentives, tasks, workflows and processes across tiers of care, provider groups and settings (22). The main challenge, however, is to translate successes within relatively small controlled environments into widely embraced and sustainable practices.

## What do we know?

Although the concept first arose in the 1970s, it was in the aftermath of the Alma Ata Conference in 1978 (23) that primary care was declared the backbone of a modern health system, being entrusted with coordination of the care provided across levels and settings (24). Primary care providers, particularly when they work in teams and in community-based centers, are uniquely suited for this role because of their ability to act as bridges with specialized services, to monitor the impact of disease management efforts and to address the psychosocial issues of those living with multiple chronic diseases (25-27). This is backed up by experiences accumulated in the past three decades indicating that strong primary care within a health system offers greater efficiency, with better health outcomes, greater public satisfaction and lower costs (28-32).

The mounting evidence in favor of strengthening primary care has not been adopted uniformly throughout the world. In the USA, for instance, 35% of primary care physicians in 2005 were practicing in isolation or in pairs, while between 1996 and 2001 the percentage of physicians in groups of 20 or more did not increase (33). Other countries, such as Spain, have made a strong commitment to primary care, achieving impressive results in just over two decades and, underscoring that it is possible to motivate individual practitioners to join multidisciplinary teams that provide continuous services guided by objective-based management models and supported by shared team objectives, while optimizing the role of each professional group (34-40).

Efforts to strengthen primary care must, however, be coupled with initiatives designed to improve communication, service coordination and continuity of care between the community and specialized facilities (41-51). This has been achieved successfully through policy reform (52, 53), thanks to the design of care packages for specific segments of the population, or within clearly delimited geographical areas. The latter, better suited

to the political and administrative structure of Europe's national health systems, seems to be the most effective and efficient approach to the integration of services (54-56). Not surprisingly, it has been shown that the availability of financial resources and strong political support are powerful drivers of positive change (57).

## Lessons from managed care

Managed care organizations in the US have developed and successfully implemented powerful instruments for the management of multiple chronic diseases through activities known as Disease Management Programs (DMPs) and Case Management Programs (CMPs) (58).

DMPs rely on multidisciplinary teams providing high-quality care based on the best available knowledge encapsulated in clinical practice guidelines and protocols for a specific disease or clinical condition. The criticisms most often leveled against them point at the risk that they could lead to parallel healthcare systems, undermining primary care (59). As for evidence regarding their effectiveness and efficiency, a recent review (60) concluded that such programs improved quality, although there is no solid evidence as to their economic impact (61).

CMPs, on the other hand, are intended for patients with complex care needs and rely on specialist case managers responsible for the coordination and integration of multiple services. Within the context of CMPs, «care» is understood in a broad sense, including all manner of provisions even if not strictly health-based, such as social or community services and those provided by volunteer groups and associations. They are particularly appropriate for the management of multiple chronic diseases, as attempts to apply different DMPs to the same individual simultaneously could lead to increased fragmentation of services. As DMPs have valuable elements that could improve the management of multiple chronic diseases the trend is to blend them with CMPs, erasing the boundaries between the two approaches (62).

Whether it would be possible to transplant this kind of programs from HMOs into whole national health systems (63, 64) remains unclear. As outlined in Chapter 4, the same issue applies to chronic disease care models (65-69), or systematic approaches to categorize inge cases based on their complexity (70-72).

## Process re-engineering

Process re-engineering is based on the principle that the changes which have taken place over the past 20 years in sectors such as banking, airlines or the car industry could complement what has been achieved with more traditional models within the health sector (73-77). It attempts to deal with complexity in a more effective manner, matching the needs of those who live with multiple chronic diseases, in time and space, with the way in which different health professionals could satisfy them in a timely manner in the appropriate spaces. One of the main contributions of a process-driven approach to the management of multiple chronic diseases is that it helps reduce or even eliminate the effect of boundaries across different levels of care and settings, as resources are mobilized in a timely manner on the basis of the needs of the patient, not on where they are available or when. The process-driven management of people with multiple chronic diseases developed in Andalusia (see Chapter 2) is a good example of the successful application of this approach (78). The emergence of computer tools for the modeling, simulation and monitoring of complex processes is bringing even more powerful ways to apply process re-engineering to the management of polypathologies.

## What do we need to know?

On the 25<sup>th</sup> anniversary of Alma Ata (80), the World Health Organization acknowledged that the epidemic of chronic disease has created many new challenges for primary care. As the need for comprehensive health system guaranteeing the continuity and coordination of health and social services increases, it will become inevitable that we assess and redefine the functions and competencies of all health professionals. How to achieve this successfully, is unclear (81). The portfolio of primary care services will probably expand, to meet the needs not only of an increasingly complex population of patients, but also of their caregivers (82).

An increased focus by family physicians on individualized care in primary care, on the other hand, would need to be balanced with their role as providers of population-based services related to health promotion and disease prevention. The risks of fragmentation are highlighted by the evolution of the family medicine specialty in Spain. When it first appeared, it was labeled «Family and Community Medicine», with the family physician acting as a clinical expert in public health. The specialty then evolved to give family physicians an increased capacity for action in the clinical sphere, without giving up

preventive activities (83, 84). As the workload increased, this led to the professionalization of public health activities and the designation of additional personnel as public health experts responsible for community health promotion programs and selective initiatives focusing on specific populations (85) in partnership with the family practitioner. Whether and how to promote or discourage the emergence of new types of health professionals will require careful attention.

Bold innovations will also be required to reduce the burden on physicians resulting from their role as integrators of clinical practice. A study of 11 family physicians across different regions of the US found that 13% of the working day was spent on coordinating care (86). Another study of 16 geriatric specialists, found that they spent 14% of their working day also coordinating care between visits, without receiving remuneration (87). Such innovations should focus on a successful reduction in the number of patients per physician or payment for care coordination, as proposed by the American College of Physicians and the American Academy of Family Physicians (88), or the involvement of other primary care team members devoted exclusively to care coordination (89,90).

Similar changes are required in nursing roles, particularly as the value of curing gives way to the value of caring. Unavoidably, nursing staff will have increased care responsibilities (91). Questions remain, however, as to how to ensure that patients trust in their judgment when they perform tasks previously limited to physicians, and that the latter do not feel threatened by them. As nurses become more autonomous, many of their current tasks will be performed by assistants and auxiliaries (92). How fast, deep and broad this transition should be is unclear.

Professional roles within hospitals are also changing. The clearest example is the role that general internists play in these bastions of specialization. For instance, in the USA the proportion of patients managed by general internists rose by 29% per year between 1997 and 2006 (93). In other countries, such as Spain, despite the development of medical specialties, general internal medicine remains the backbone of most hospital medical services (94). This has created opportunities for breakthroughs in patient care. In 1996 a study into coordination between tiers of care led to the proposal for a partnership between primary care generalists in the community, and internists as hospital generalists, with a view to introducing a shared care model (95). In 1997 the Spanish Society of Internal Medicine and the Spanish Society of Family and Community Medicine proposed a model for coordination between tiers of care based on this family physician-general internist partnership. The proposal recognized the role of the family physician as the patient's

primary agent, while the general internist, acting as a generalist within the hospital, would play the role of the second bridging agent within the hospital context. This bridging agent would not compete with the function of the family physician, but would facilitate the integration of services based on a privileged position, that of the multifunctional hospital professional, with access to diagnostic resources at that level, and a «bed» resource when needed (96, 97). One of the most innovative and genuine contributions of this approach was the assigning of joint leadership to family physicians and general internists, with responsibility for optimizing communication and aligning services through different levels of care. A number of studies have analyzed the impact of this approach (98, 99), underscoring an improvement in professional satisfaction (100, 101). How it compares with other models of care coordination, however, remains unknown (102, 103).

Another area that deserves attention is the web of signs, symptoms and ailments that prevents most patients with multiple diseases from expressing their real concerns in a clinical care environment. Authority over the predicament of these patients can only be gained through shared understanding, and the primary care physician is in a privileged position to achieve it, particularly if equal importance is given to the patients story of the illness, the clinicians story of the illness and the relationship between clinician and patient.

Another area that requires attention is the role to be played by primary health care teams, as multiple chronic diseases challenge all of the traditional roles and workflows within the health system (104-106). Some authors believe that health teams are incompatible with personalized care (107). Others advocate for teams with greater flexibility within a single management structure bringing together primary care and hospitals (108).

The impact of health policies combining process re-engineering with decentralized clinical management units has not yet been assessed (109). Special consideration will need to be given to appropriate quality certification and accreditation policies for the services provided within this context (110, 111) and at the hospital level (112, 113). New systems will be required for the classification of patients on individual and population bases, particularly to facilitate the appropriate allocation of resources (114, 115). Such systems would need to be carefully designed and evaluated, to avoid discriminating against older populations or any other group with a high proportion of patients living with multiple chronic diseases.

## What innovative strategies could fill the gaps?

Filling the gaps identified above will require unprecedented levels of collaboration across all levels and groups of stakeholders in the health system. Any effort will depend on reaching agreement, first and foremost, on the terminology that should be used to communicate within and across traditional boundaries. The global taxonomy being developed with support from the OPIMEC platform and the clinical categories related to polypathology described in Chapter 2 represent important steps along this path (116). These will allow for efficient and objective identification of populations of people living with multiple chronic diseases with similar healthcare needs (117-120) and clinical characteristics (121) enabling an evaluation of the roles of different members of the healthcare team (122) and caregivers (123), and the assessment of different interventions to optimize their quality of life (124) and the available human and financial resources.

Another area well suited to global collaboration through a platform such as OPIMEC is the exploration of the optimal role that algorithms, care paths or integrated care process in general could play in the transformation of clinical services.

Given the multidimensional nature of such interventions and the dynamic nature of the relationships among different stakeholders, tools from simulation-driven training programs and complexity sciences could play an important role in any research effort designed to promote new health professions, to re-define existing ones, or to optimize the impact of innovative interventions to improve patient care , health services and policies (125, 126).

Assessing the effectiveness and acceptance by the population of management strategies based on new roles of health professionals is essential for their promotion.

Lastly, it will be vital to promote the creation of a global association of people living with multiple chronic diseases as a means of harnessing the power of patients and caregivers as agents for change.

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

This book is continuously evolving at [www.opimec.org](http://www.opimec.org)