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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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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](http://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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## Foreword

We have for some years been witnessing a profound change in our perception of what healthcare should be. Rather than a vision of illness based on episodes requiring a series of interventions of greater or lesser intensity, but which are nonetheless limited in time, we are now very often faced with chronic health problems which accompany sufferers over a number of years. In many cases the same person will suffer from several such chronic diseases simultaneously, making care especially complex, in particular if it is not tackled from an appropriate perspective. We are now beginning to understand that care for people with multiple chronic diseases demands a completely different approach to that which served as the basis for the design of our health systems and traditional working processes.

In Andalusia, a region of Spain located in the far south of Europe, we set out at the start of this decade to introduce substantial improvements in the public healthcare system. The Health Department of the region's government, the Junta de Andalucía, with the extensive involvement of healthcare professionals, planned a number of initiatives structured around an ambitious plan which is still today being deployed. Perhaps the most novel aspect was an attempt to act from the citizen's perspective. By looking through the eyes of the patient, by placing citizens at the heart of the system, we radically altered our vision of the way in which healthcare structures are designed. Continuity of care, coordination among professionals and levels of care, or holistic care, emerged as the major unresolved challenges. Above all, though, we restored a complete vision of the person, each with a whole set of individual health problems. This gave new life to the words of William Osler: «it is more important to know what type of person has the disease, than to know what type of disease the person has». When we reconsidered our way of dealing with the most significant health problems, restructuring healthcare operations to make them more appropriate and effective, there emerged the need to define patients with various chronic diseases and to reformulate the way in which every aspect of their complex situation is handled from a healthcare and social perspective. Nursing professionals, specialists in family medicine, internal medicine and other fields of knowledge performed intensive work, using a process re-engineering methodology

to define best practice in the handling of such patients, to be applied in a public health system which caters to more than 8 million people. After defining what we refer to as the «poly pathological patient», we developed further initiatives to improve care, such as the patients' school, intended to provide chronic disease sufferers with the skills to manage their own conditions, or the multi-channel health platform «informarse es.salud», which provides a number of information and self-help tools.

Along this hugely exciting journey we met health professionals from other regions of the world who shared our concerns and preoccupations, and who were already devising new solutions for complex chronic disease in their own areas. To provide an ongoing basis for contact among experts in complex chronic disease from the five continents, we set up a forum for interaction and shared reflection: OPIMEC. OPIMEC is the Spanish acronym for Spanish acronym for the Observatory of Innovative Practices for Complex Chronic Disease Management. Its aim is to promote the generation of knowledge about this problem and to share innovative experiences worldwide through open, networked cooperation and participation. An increasing number of professionals and experts from different countries now meet up in this virtual forum to exchange experiences and contribute new approaches and concerns.

The gathering staged in Seville in 2009 by the Andalusian School of Public Health and OPIMEC gave rise to the idea of turning this emerging knowledge into a book, to serve as a guide for those who are new to this highly complex issue and make a significant contribution to the consolidation of what is still a new concept, while also identifying best practice approaches based on the soundest scientific evidence available.

It is for me a source of genuine pride to be able to present this book, which has come to fruition in such a short time thanks to the enthusiastic participation and brilliant contributions of 55 experts from 18 countries. I sincerely believe that the text you hold before you summarises the best knowledge yet available about poly pathology, its implications for care and administration, possible approaches, embracing health promotion, prevention, self-management and responses covering the entire healthcare itinerary, including supportive and palliative care, along with promising ideas regarding the potential of information and communication technologies, robotics, genomics and nanotechnology. It also contains a valuable chapter on the taxonomy and language of



this emerging area, an essential aspect in ensuring that we truly know what we are referring to at each stage.

I am sure that in this helpful and fascinating collective work you will find innovative strategies which could help fill the gap between what we know and what we need to know in order to satisfy the needs and expectations of a growing number of vulnerable people throughout the world.

Representing as it does an open approach to knowledge, in addition to this paper edition you can also access the book on the Internet free of charge in English and Spanish. In order to keep this initiative alive I would warmly invite you to take part in its future editions via [www.opimec.org](http://www.opimec.org), thereby ensuring that it continues to evolve. Please join us in tackling the huge collective challenge of improving care for people with multiple complex chronic diseases worldwide. With your help, we can do it.

María Jesús Montero Cuadrado  
Health Minister,  
Andalusian Government  
Spain



# Why Multiple Chronic Diseases? Why now? What is going on around the world?

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

## The price of success

*«In this fallen world everything good has unintended evil consequences, every Yang has a Yin» .(1)*

In 2004, two scholars announced that they had discovered the earliest known version of a poem by Sappho, the Greek poetess known as the Tenth Muse (2). It was written on a fragment of a papyrus used to cover an Egyptian mummy kept at the University of Cologne, in Germany. The poem, which had been transcribed at least 300 years after the death of Sappho, became one of the most complete examples of her work available to date.

The poem is a compact masterpiece. In just 12 lines, it captures the poetess's insights into her own ageing process and the plight of humans as we grow old. Her words, which resonate more than ever 2700 years later, read as follows (those in brackets were missing from the fragment, and were filled in by the translator (3):

*«[You for] the fragrant-blossomed Muses' lovely gifts  
[be zealous,] girls, [and the] clear melodious lyre:*

*[but my once tender] body old age now  
[has seized;] my hairs turned [white] instead of dark;*

*my heart's grown heavy, my knees will not support me,  
that once on a time were fleet for the dance as fawns.*

*This state I oft bemoan; but what's to do?  
Not to grow old, being human, there's no way.  
Tithonus once, the tale was, rose-armed Dawn,  
love-smitten, carried off to the world's end,  
handsome and young then, yet in time grey age  
o'ertook him, husband of immortal wife.»*

In the last four lines, Sappho refers to a myth that was very popular in the 7<sup>th</sup> century BCE as a means to convey the suffering associated with the decay of human bodies, as they age.

According to this story, the Goddess of the Dawn, Eos, had fallen in love with Tithonus, a Trojan. As she could not conceive of a life without her mortal lover, Eos persuaded Zeus to grant Tithonus eternal life. Zeus, however, took Eos's request literally. He made Tithonus immortal, but did not give him eternal youth. As a result, Tithonus started to grow old, becoming progressively debilitated by multiple chronic conditions and demented. The myth ends with Eos trying to mitigate Tithonus's suffering by transforming him into a grasshopper.

At the dawn of the 21<sup>st</sup> century, millions of people around the world are facing the same challenges illustrated in the myth of Tithonus and in Sappho's poem. The extraordinary level of control of acute conditions and the lengthening of life expectancy achieved by humans in the 20<sup>th</sup> century is now ushering in a global epidemic of chronic diseases and infirmity.

The high prevalence of chronic conditions is already having a major effect on mortality data across the world. In a landmark report entitled Preventing Chronic Diseases: a landmark investment, the World Health Organization (WHO) estimated that 60% of deaths around the world in 2005 were already due to chronic diseases, with 80% of the total occurring in low- to middle-income countries (4). In fact, chronic diseases are the leading cause of death in every country in the world, except for those with the lowest levels of income. Even in the latter, however, the gap separating them from infectious diseases is narrowing (5). To compound this, depression and not physical injury, is now the leading cause of years lost to disability in the world (6).

Sadly this epidemic, which has been the subject of many recent reports (7), is being underestimated and neglected (8).

## The emergence of polypathology

The high prevalence of chronic diseases has created yet another new phenomenon: a growing number of people are living with multiple chronic diseases.

This phenomenon includes not only those individuals with an index disease that has triggered secondary conditions (e.g., a person with diabetes who is affected by associated retinopathy and neuropathy), but also those in whom two or more diseases co-exist (e.g., people with diabetes, cancer and Alzheimer's disease at the same time).

As will be discussed in more detail in the next chapter, there is no accepted terminology for this phenomenon. The labels that seem to be used most frequently seem to be «co-morbidity», «polypathology», «poly-pathology», «pluripathology», «pluri-pathology», «multi-morbidity», «multimorbidity», «multi-pathology» or «multipathology» or «complex chronic disease» (Chapter 2). Polypathology will be the term used most often throughout this chapter.

Just like the fragments of Sappho's poems, however, there appears to be a patchy picture of knowledge on the prevalence of polypathology and its associated societal burden. Most reports provide data on specific disease clusters, in high risk groups, or in specific regions or countries (9). Very few, if any, seem to contain original data on the prevalence of several diseases, detected and documented simultaneously, across all age groups, worldwide.

A refined search of MEDLINE conducted on April 14, 2009 (Figure 1), complemented by a search of Google and Google Scholar on August 22, 2009, revealed a few glimpses of what may be happening.

Figure 1

Search strategy

ORGAN-SYSTEM
1 polypatholog:.tw,mp. (5)
2 polypatholog:.tw,mp. (50)
3 pluripatholog:.tw,mp. (16)
4 polypatholog:.tw,mp. (5)
5 polypatholog:.tw,mp. (50)
6 pluripatholog:.tw,mp. (16)
7 (multiple adj5 condition).mp. (754)
8 (multiple adj5 illness).mp. (536)
9 multidisease.mp. (13)
10 multimorbid.mp. (142)
11 (multiple adj3 morbid).mp. (42)
12 (complex adj5 condition).mp. (813)
13 (complex adj5 illness).mp. (393)
14 (complex: adj3 disease).ti. (1296)
15 (multiple adj3 disease).ti. (1026)
16 or/1-15 (5043)

Database: Ovid MEDLINE(R) <1950 to April Week 1 2009>.

Source: U.S. National Library of Medicine. Ovid Medline [Web site]. [access April 1<sup>st</sup>, 2009]. Available at:<http://ovidsp.tx.ovid.com/>

One of the main messages from the patchy literature is that the estimates of the prevalence of polyopathy among adult members of the general public vary widely, with figures ranging from 17% to just over 50% (10-13).

A more consistent finding is that people with polyopathy may represent 50% or more of the population living with chronic diseases, at least in high-income countries. For instance, a systematic review of 25 Australian studies conducted from 1996 to 2007 found that half of the included elderly patients with arthritis also had hypertension, 20% had cardiovascular disease (CVD), 14% diabetes and 12% a mental health condition. Similarly, over 60% of patients with asthma reported living with arthritis, 20% CVD and 16% diabetes; and of those with CVD, 60% also had arthritis, 20% diabetes and 10% had asthma or mental health problems (14). A study of a random sample of 1,217,103 patients from the United States who had been receiving Medicare services for over a year (and so were 65 or older) showed that two thirds (65%) had multiple chronic conditions (15). Studies of patients admitted to hospitals in Spain also show a prevalence of polyopathy ranging from 42% to just over 57% (16, 17).

Data from other studies show even higher prevalence levels among people living with specific chronic diseases. An analysis of five randomly selected clinical trials that included patients with hypertension in Canada in 2003 revealed that 89% to 100% had multiple chronic conditions with a mean number of chronic conditions that ranged from 5.5 to 11.7 (18). A similar pattern was found among people living with chronic obstructive pulmonary disease as their index condition in Italy, where 98% of participants in a large cohort of patients had been prescribed at least one non-respiratory drug. The co-existing disease was cardiovascular in 64% of cases, diabetes in 12% and depression in 8% (19). A prevalence of polyopathy of 91% was also found in a sample of indigent, predominantly African-American patients in the United States (20).

As expected, the prevalence of polyopathy seems to progress with age. An assessment of two large Australian national surveys conducted in 2001 and 2003 showed that the proportion of people who live with three or more chronic conditions increased from 34% for those members of the general public with ages between 20 and 39 years, through 57% between 40 and 59 years, to 80% between 60 and 74 years, and 86% at 75 years or more (12).

It is difficult to determine the proportion of people living with different numbers of co-existing diseases not only because of the scarcity of studies, but because of the use of

different metrics across those available. A Danish analysis of data gathered over two decades suggested that four or more diseases were present in 7% of people with ages between 45 and 64 years, increasing to 30% between 65 and 74 years and to 55% among those 75 years and older (21). Analyses of Medicare beneficiaries have shown that 23% live with five or more diseases (22). In Spain, it was estimated that people with ages between 65 and 74 years had a mean of 2.8 chronic conditions, while those over the age of 75 had 3.2 diseases on average (23). A French study of 100 patients aged 80 and over who were hospitalized in a geriatric unit showed that the mean number of recognized diseases per patient was 4.1 (range 1-10) (24).

In addition to older age, multivariate analyses have found that obesity, being female with low socioeconomic status, and living alone are associated with a significantly greater probability of having three or more chronic illnesses (12). In addition to the association with gender and older age, another study showed an increased risk of polyopathy among people with low levels of education, with health insurance and those living in a home for the elderly (10).

Data on the mortality rates by number of chronic diseases in people with polyopathy are also limited. A study of individuals aged between 55 and 64 years that used Veterans Health Administration health care services between October 1999 and September 2000 showed a 5-year mortality rate that increased from 8% among people with two conditions, through 11% for those with three, to 17% for those with four or more (25).

Data on polyopathy from low- and middle-income countries are sparse also. In a study of 844 patients with heart failure who attended a hospital in Soweto, South Africa, 172 (24%) also had renal dysfunction, 83 (10%) coronary artery disease, 18 (2%) a history of acute myocardial infarction, 86 (10%) diabetes, 72 (10%) anemia, 58 (7%) stroke, and 53 (6%) atrial fibrillation (26). A survey of households substantially affected by serious illness in two counties in China identified 2,259 people with chronic disease, of whom 2,140 (95%) had one condition, 110 (5%) two, and 9 (0.4%) three (personal communication) (27).

Only one of the identified studies provided data on the prevalence among children or adolescents. This effort, which used data from the Registration Network Family Practices in The Netherlands, showed that 10% of people from birth to 19 years of age are likely to have multiple chronic diseases (10).



## Why this book now?

Our limited knowledge about polypathology is not only restricted to an understanding of its prevalence. In 2006, the Veterans Health Administration (VHA) in the United States organized a conference entitled Managing Complexity in Chronic Care, motivated by the risk of having insufficient funds to meet the health service needs of its target population (e.g., war veterans, active service members in time of war and people affected by national emergencies). This concern was fueled by the realization that 96% of Medicare expenditure at that time was already being directed to people living with multiple chronic diseases (28).

The insights generated before, during and after this event were published as nine short articles in a special supplement of the Journal of General Internal Medicine in December of 2007 (29). An accompanying overview listed nine key research topics that had been identified as a result of the deliberations of the participants about unmet care needs for people living with multiple chronic diseases (Figure 2).

Figure 2

---

### Research topics in the management of patients with complex chronic care needs identified at the SOTA conference sponsored by the VHA in 2006 (28)

1. Characterize high risk cohorts of patients with Multiple Chronic Conditions (MCCs) and social complexity, including health services impact. From this work develop and priority list of MCCs and social complexity for targeted interventions
2. Synthesize/systematically review literature of interventions that relate to MCCs and complex care needs for patients with social complexity
3. Advance work in outcomes assessment, including measures of comprehensive care needs and optimized for patients with MCCs
4. Increase the evidence-base of efficacy and effectiveness studies to support guidelines that are adaptive to MCCs and social complexity for high priority complex patients
5. Development of more optimal performance measures that reflect complex morbidity including focus on patients self-management and coordination of care
6. Evaluate systems changes that organize care around MCCs and social complexity of illness management such as:

- New team-based strategies for care in complex chronic care management
  - New non-MD team member roles increased role in care
  - The role of and different designs of an «advance medical home» in managing patients with complex care needs
  - The role of care sharing between physician specialties and service lines in optimal management of care
  - Self-management support, including group-based learning structures
  - High performance systems of care for patients with high priority MCCs
  - Technology assistance for patients with visual, hearing, and other physical limitations in optimizing complex care management
7. Examine best practices in patient-physician communication strategies for care management decisions for patients with MCCs or with social complexity:
    - What are best methods for eliciting patients with preferences in light of care complexity, and engaging patient social support structures (e.g. family)?
  8. Evaluate new Health Information Technology strategies to support complex care management to advance knowledge of:
    - What decision support tools are needed for patients with complex care needs?
    - How can patient registries best support care management for patients with MCCs?
    - What type of Patient directed HIT tools can be developed for optimizing self-management for such patients?
  9. Identify best practices for integration of rehabilitation services into patient management strategies for patients with complex chronic care needs

Completely unaware of the unfolding VHA efforts, leaders at the Andalusian Ministry of Health in Spain also identified the growing prevalence and burden of complex chronic diseases among its target population, making it a top priority for action. As they had supported a long collaborative effort to develop, implement and evaluate a care process to optimize the management of polyopathy, at all levels of their regional health system, they were fully aware of the slowly growing interest in this topic in other parts of the world. They were also conscious of the almost complete absence of meaningful collaboration among leading groups. They recognized that most of the available work

had evolved in isolated pockets, missing important opportunities for effective collective learning and for the creation of the large-scale joint efforts required to meet the needs of those living with multiple chronic diseases.

Back in 2006, there was no single place, physical or digital, in which interested people could collaborate across traditional institutional, geographic, professional, linguistic, political, disciplinary and cultural boundaries, to face the challenges created by poly pathology.

Against this background, and encouraged by the rapid development and penetration of powerful online resources for collaboration (e.g., wikis, social networking tools), the Andalusian Ministry of Health decided to promote the creation of a global observatory designed to promote the exchange of knowledge and joint efforts among individuals and organizations interested in the management of complex chronic diseases, anywhere in the world.

The Observatory, which is known as OPIMEC (the Spanish acronym for Observatory of Innovative Practices for Complex Chronic Disease Management), is available in English and Spanish at [www.opimec.org](http://www.opimec.org). In essence, it is a collaborative virtual environment that uses state-of-the-art tools to allow health professionals, researchers, policy-makers and the general public to:

- Access and contribute to the development of a common language with which to improve communication about poly-pathologies across traditional boundaries (supported by wikis).
- Identify, classify, suggest and adopt innovative practices that could improve quality of care in their own settings (supported by Google Maps).
- Communicate and collaborate with individuals who share an interest in meeting the challenges associated with poly pathology (supported by online social networking tools).

In mid-2008, the members of the International Advisory Committee of OPIMEC, a group of leading experts in chronic disease management from North America, Europe and Australasia, suggested that the Observatory focus specifically on poly pathology, as this was regarded not only as neglected, but also as a source of important opportunities for «glocal» impact (global and local, at the same time).

In March 2009, the Andalusian Ministry of Health convened a meeting in Seville of its key regional leaders in the management of chronic diseases and their closest collaborators

from other regions of Spain and around the world. Together, the participants identified ten poorly-understood areas related to polypathology that they felt could benefit from international collaborative initiatives:

- Epidemiological issues.
- The language of polypathology and assessment of complexity.
- Prevention and health promotion.
- Disease management models.
- Patient education and self-management.
- Primary care and integrated management processes.
- Supportive and palliative care.
- Demedicalization of care (with emphasis on complementary and alternative interventions).
- Economic, social and political implications.
- The Promise of Genomics, Robotics, Informatics/eHealth and Nanotechnologies (GRIN).

Collectively, the event participants expressed strong interest in using OPIMEC to co-develop and share a body of constantly evolving knowledge that could be made available to anyone, anywhere in the world, at any time, in digital form and free of charge. As a catalyst for this ambitious global collaborative effort, the group decided to produce a book, in digital and paper form, in English and Spanish, which could be launched during Spain's presidency of the European Union in the first half of 2010, and made available to anyone interested, free of charge.

## The approach

During the March 2009 meeting, participants were invited to lead (main) or identify lead contributors for specific book chapters focused on each of the neglected areas that they had identified.

By the end of the month, all chapters had been assigned to a lead contributor who had committed to having the first draft ready by the summer of 2009. At that point, the initial

senior editorial group had also been confirmed (Dr. Lyons joined the editorial group at the end of the year), and a technical support team and a roster of potential contributors had been established.

All of the lead contributors agreed to follow a series of principles to ensure maximum transparency to future audiences, and to prevent any unnecessary perception of conflicts of interest or bias. They:

- Used language that would be accessible to different potential audiences, including policy-makers, clinicians, managers and researchers. A lay summary would make the essence of each chapter easy to grasp for the general public.
- Disclosed their affiliation with organizations that may have an interest in the management of poly-pathologies in general, or with a specific topic in particular.
- Made explicit any personal or organizational biases that may influence the tone and emphasis given to the topic being addressed.
- Avoided over-emphasizing or focusing just on issues that related to their professional activities or organizational goals, be they political, financial or academic.
- Acknowledged, whenever possible, the work of individuals and organizations with opposing views or with competing interests.
- Made their contributions without financial or political incentives.

The contributors also agreed to follow a structured format for each of the chapters, with the following sections:

- A *vignette* outlining a vision of the future using a 20- to 30-year horizon.
- A brief *summary* highlighting the main points covered in the rest of the chapter, using language that could be understood by any interested reader.
- *Why is the topic important?* This section described the magnitude of the challenge associated with this specific topic, providing as much data as possible, including all regions in the world, while trying to address the perspectives of different groups of stakeholders (patients and their caregivers, policy-makers, managers, funders and academics).
- *What do we know?* Here, contributors summarized the research literature available on the topic, highlighting the implications for each of the above groups of stakeholders.

In each chapter, contributors ensured that they had drawn from the initial literature search, as well as from their own collections of resources.

- *What do we need to know?* This section emphasized the knowledge gaps that exist around this topic, and why it would be important to fill them.
- *What innovative strategies could fill the gap?* The contributors ended each chapter with proposed innovative efforts that could be pursued to fill the identified gaps, focusing on methodological issues, resource needs (technological, financial and human) and the role that OPIMEC could play in the process.

Six of the chapters were produced initially in Spanish and four in English (those that dealt with epidemiological issues, prevention and health promotion, supportive and palliative care, and demedicalization of care).

One of the senior editors (FM) supported contributors writing in Spanish and another (AJ) those working in English. The latter, fluent in both languages, was responsible for reviewing all of the initial drafts, for harmonizing their content, eliminating redundant content, and identifying areas for improvement.

The revised draft chapters, with suggested changes, were sent to each of the lead contributors, who in turn produced refined versions. In most cases, two iterations of revisions were completed before the initial drafts were considered to be ready for translation.

Once each of the drafts had been translated to the alternate language, the same bilingual senior editor (AJ) reviewed them for accuracy and, whenever appropriate, edited the content further, in both languages.

The translated files were then sent to the respective lead contributors for verification and approval. Once approved by them, the draft chapters were uploaded to the OPIMEC platform by the support team, in a format that included separate interactive sections designed to allow readers to make comments and suggestions for improvement (Figure 3).

Figure 3

## Interactive table of contents with a section sample



1. Why Multiple Chronic Diseases? Why now? What is going on around the world? (In development)
2. The language of poly-pathology (In development)
3. Prevention and health promotion (In development)
4. Disease management models (In development)
5. Patient education and self-management (In development)
6. Primary care, institutional services and integrated management processes (In development)
7. Supportive care and palliative care (In development)
8. Integrative medicine (In development)
9. Socioeconomic implications (In development)
10. The promise of Genomics, Robotics, Informatics/eHealth and Nanotechnologies (GRIN) (In development)
11. Towards a global collaborative approach to complex chronic disease management (In development)

**What do we know?**

The terms that have traditionally been used in relation to patients with chronic disease usually reflect the silos of the health system, either emphasizing the needs of individual diseases or organs.

The limited work that has been done in relation to multiple chronic diseases has focused mostly on <comorbidity>, understood mostly in terms of a primary disease and its associated conditions (see below). Other terms, more related to health services or overall health status, such as frequent flyers, hyper-attenders, polymedicated, frailty and disability, are also frequently used. However, there is a lack of standardization in the terminology employed both by clinicians and investigators in this field. We lack a poly-pathologic disease thesaurus, an unambiguous taxonomy with widely accepted, easy-to-follow and valid definitions of terms, and a clear framework designed to promote the exploration of the relationship among them.

The US National Library of Medicine's Medical Subject Headings (MeSH) provides the broadest coverage of concepts for health, but it lacks many terms related to the issues confronted by patients living with multiple chronic diseases. The World Health Organization (WHO)'s International Classification of Diseases (known as ICD), is widely used within many health systems around the world, but it is little more than an unidimensional ordering of terms describing medical concepts with little relevance for chronic complex patients. Even SNOMED CT (Systematized Nomenclature of Medicine- Clinical Terms), the most comprehensive clinical vocabulary available in any language, lacks specific terms to enable a clear and reproducible description of the conditions, the interventions or the outcomes achieved in any case in which two or more chronic diseases co-exist (1). The only significant attempt to classify disease management interventions through

Source: OPIMEC. [Web site]. [access May 5<sup>th</sup>, 2010]. Available at: <http://www.opimec.org>

While the chapters were being uploaded, the editors and lead contributors produced a list of peers they felt could provide useful comments on each of the drafts, selecting them from among colleagues they knew or the authors of key articles they had used as references. The editors then sent an electronic message to the members of this list, inviting them to read the chapters and make comments, either anonymously or by registering as members of the OPIMEC community. In all cases, the support team was available to provide technical assistance under supervision by one of the editors (AC).

Throughout the process, the terms contributor and contributorship were considered to be more consistent with modern approaches to acknowledging the work of members of collaborative groups than the more traditional author or authorship (30).

A minimum of a month after the chapters were uploaded to the platform, the editors reviewed all of the comments received and produced lists of substantive changes that were sent to the lead contributors for incorporation into the drafts.

The revised versions were then reviewed thoroughly by the editors (RS, RL and AJ in English, and PM, AC and AJ in Spanish), who could make modifications to the main text online. Those individuals who made substantive comments, as judged by the editors by consensus, were recognized as book contributors.

## The output

By the end of February of 2010, less than a year after the original meeting in Seville, the chapters that we present in this book had been completed, revised in draft form at least twice, and approved by the editors. The eleventh chapter was added soon before the submission of the final version of the paper edition of the book in April 2010.

Contributions were received from individuals living in all of the inhabited continents. Most of them, however, were made by colleagues who were approached at the outset by the editors and by members of their immediate teams or circles of collaborators.

Despite their ease of use and the availability of technical support at all times, some contributors preferred to use traditional electronic mail to produce content over the online resources available on the OPIMEC platform. This made the editing process difficult at times, as contributors would send different versions of their work directly to individual editors, creating unnecessary confusion and duplication of effort.

The editors, on the other hand, communicated mostly by electronic mail, complementing their frequent (at least weekly) text-based interactions with online videoconferences and in-person meetings whenever possible.

The conversion of the contributions into homogeneous versions in English and Spanish was not a straightforward process. The translations, which were mostly precise reflections of the original text, required heavy editing to make them flow as comfortably as possible for readers in the alternate language. This led to inevitable mismatches between the versions, which bilingual readers will recognize easily in most cases.

Another interesting aspect of this effort was the process to decide when to consider the digital content that was emerging through such a diverse collective of contributors



to be ready for publication in book form. In most cases, the threshold was determined by the absence of comments from existing or new contributors. In the remaining few, the editors had to decide, by consensus, that the chapter was good enough for release in static form. Continued revision of these few chapters was not possible because of the limitations imposed by the publishing timelines and the need to launch the content as a paper-based book in early June 2010. Nevertheless, having the entire contents available online, through the OPIMEC platform, should enable any interested reader to make suggestions as to how to improve on what has been produced so far.

In any case, the book achieved its original overarching objective: to act as a powerful stimulus for collective effort, across traditional boundaries, among people interested in improving the management of complex chronic diseases. Without the incentive associated with the creation of something so tangible, or the pressure generated by publication deadlines and launch dates, it would have been difficult to achieve so much, in so short a period of time, and with no financial incentives. Along the way, those who responded made a substantial and generous attempt to summarize the limited knowledge available around this important and seriously neglected area, while proposing innovative strategies to fill the gap between what is known and what should be done to meet the needs and expectations of a growing number of vulnerable people in every society in the world.



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### *Contributors*

Alejandro Jadad wrote the first draft of this chapter in English and approved its Spanish translation. All of the other editors (Andrés Cabrera, Francisco Martos, Renée F. Lyons and Richard Smith) reviewed the chapter and approved it, with minor comments. These, together with valuable contributions from Kerry Kuluski, were incorporated by AJ into the final version that was included in the paper-based book.

Responsibility for the content rests with the contributors and does not necessarily represent the views of Junta de Andalucía or any other organization participating in this effort.

### *Acknowledgments*

Joseph Ana, José Miguel Morales Asencio, Bob Bernstein, Murray Enkin, John Gilles, Marina Gómez-Arcas, Rodrigo Gutiérrez, Jacqueline Ponzo and Ross Upshur made insightful comments on the chapter that did not lead to changes to its contents. Such comments, which were greatly appreciated, were considered for inclusion in other chapters of the book.

### *How to reference*

Jadad AR\*, Cabrera A, Martos F, Smith R, Lyons RF. [\*Main contributor] Why Multiple Chronic Diseases? Why now? What is going on around the world?. 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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## The language of polypathology

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

### Vignette: How it could be

*Paula, a 23-year-old medical student, is interviewing and examining Mr. Gupta, who has a long history of diabetes, arthritis and Parkinson's disease. As is now normal, she ensures that the 10 cameras in the consulting room capture every one of her actions, as well as the conversation with Mr. Gupta. It is still difficult for her to believe that her grandfather had to use pen and paper to take a patient's medical history, or that her father (another doctor; it seems to run in the family), had to type his impressions with a mouse on what was then called a computer.*

*She is very grateful to the unprecedented global effort that was made in the second decade of the 21<sup>st</sup> century to develop a taxonomy that now enables any health information system to record, code and classify each of her clinical and research activities, and report her outcomes, automatically, without any additional effort on her part. She is also very pleased to know that she is not part of a privileged minority. Every health professional, researcher, policy maker, manager, funder and member of the public interested in multiple chronic diseases uses this taxonomy, which is available anywhere in the world, free of charge, in over 100 languages and via multiple formats, technological platforms and media. She is also proud of the fact that, in keeping with the openness that inspired its creation, the taxonomy can be modified by her or by anyone else, from anywhere on the planet, at any time. She knows that her suggestions will be taken seriously by those elected to ensure that the taxonomy reflects the needs of its users and contributes to a people-centered sustainable health system.*

## Summary

- There is no accepted or acceptable terminology to identify, characterize, describe, code and classify what happens to people who live with multiple chronic diseases.
- Such terminology could play a valuable role in efforts seeking to transform management and research efforts in these complex cases.
- Existing coding and classification resources could be complemented to capture the nuanced nature of multiple chronic diseases.
- Co-morbidity is a term that appears in most terminologies, but it does appear to refer, mostly, to multiple conditions that are associated with or secondary to a main disease.
- Newer terms, such as pluri-pathology or poly pathology, may be more appropriate as they tend to focus more on cases in which there is no primary or dominant disease.
- Any terminology or taxonomy must take into account terms of great relevance to multiple chronic diseases, such as frailty, disability, and complexity.
- The Internet, and particularly Web 2.0-powered resources, such as OPIMEC, could promote global collaborative efforts that could accelerate the development of a robust and widely supported taxonomy for multiple chronic diseases.

## Why is this topic important?

Without valid, easy-to-use and widely acceptable tools to capture and communicate what happens to people who live with multiple chronic diseases, it would be very difficult for policy makers, clinicians, researchers, managers, patients, caregivers and any other interested group to pursue the unprecedented efforts that are required to enable the health system to meet the needs of this underserved population.

## What do we know?

The terms that have traditionally been used in relation to patients with chronic disease usually reflect the silos of the health system, emphasizing the needs of either individual diseases or organs.



The limited work that has been done in relation to multiple chronic diseases has focused mostly on comorbidity, understood chiefly in terms of a primary disease and its associated conditions (see below). Other terms, more related to health services or overall health status, such as frequent flyers, hyper-attenders, polymedicated, frailty and disability, are also frequently used. However, there is a lack of standardization in the terminology employed both by clinicians and investigators in this field. We lack a poly-pathologic disease thesaurus, an unambiguous taxonomy with widely accepted, easy-to-follow and valid definitions of terms, and a clear framework designed to promote the exploration of the relationship among them.

The US National Library of Medicines Medical Subject Headings (MeSH) provides the broadest coverage of concepts for health, but it lacks many terms related to the issues confronted by patients living with multiple chronic diseases. The World Health Organization (WHO) International Classification of Diseases (known as ICD), is widely used within many health systems around the world, but it is little more than an unidimensional ordering of terms describing medical concepts, with little relevance for chronic complex patients. Even SNOMED CT (Systematized Nomenclature of Medicine- Clinical Terms), the most comprehensive clinical vocabulary available in any language, lacks specific terms to enable a clear and reproducible description of the conditions, the interventions or the outcomes achieved in any case in which two or more chronic diseases co-exist (1). The only significant attempt to classify disease management interventions through a comprehensive taxonomy was proposed in 2006 in relation to cardiovascular diseases (see section The importance of a common taxonomy for chronic disease interventions) (2).

The following is a brief description of the most widely used terms:

## Comorbidity

In 1990, the US National Library of Medicine introduced the MeSH term comorbidity defining it as the presence of coexistent diseases, or diseases which have a compounding effect, dating from an initial diagnosis or referring to a primary condition which is the subject of study. This approach, which emphasizes the existence of a primary or core disease and a constellation of associated conditions (only sometimes secondary to the primary disease) makes comorbidity a vertical concept. Because of its verticality, patients can be labeled differently depending on the clinician's point of view. For instance, a patient with advanced diabetes who presents congestive heart failure, peripheral neuropathy and incipient nephropathy could be assigned different primary diseases depending on

whether she is being managed by an endocrinologist, a cardiologist, a neurologist or a nephrologist.

Seasoned clinicians who devote most of their time to the management of patients with multiple diseases suggest that comorbidity be classified in three groups depending on the relationship between the index disease and the accompanying conditions (Bob Bernstein, personal communication):

- Random: These are the diseases that occur together with a frequency no different from that of the individual conditions separately in the population. An example is the co-existence of hand warts and osteoarthritis.
- Consequential: This is the usual type of co-morbidity included in most classification systems, and refers to conditions that are patho-physiologically part of the same process, such as diabetes and hypertension, occurring together with a frequency that is much greater than what could be explained by chance. These co-morbidities, though interesting, are predictable.
- Cluster co-morbidity: This is what happens when there is non-random clustering of health conditions without an evident underlying patho-physiological cause, as occurs with obesity and cancer, for instance. This provides an opportunity for new discoveries-either new understandings of patho-physiology, or a new appreciation of the nature of complexity. This term could be considered equivalent to poly-pathology, as described below.

Terms that would translate as multimorbidity, polypathology or pluripathology are often used interchangeably with comorbidity in German, French and Spanish (3-12). Polypathology, however, may offer some advantages in its own right, as a distinct term.

## Polypathology

Polypathology (also described as pluripathology) is widely used in Spain as a concept that is complementary (not antagonistic) to comorbidity. This concept has emerged out of the need to address the population of people who live with two or more chronic symptomatic diseases more holistically. In these patients it is difficult to establish a predominant disease, as all those that co-exist are similar in terms of their potential to destabilize the person, while generating significant management challenges. Consequently, it is a more transversal concept that focuses on the patient as a whole and not on a disease or the professional who cares for the patient.

In 2002 a set of criteria for polypathology was proposed in Andalusia, and this has since then been adopted by several regional health authorities (13) serving a population of over 8 million people. Its prognostic value has been validated through prospective cohorts (14) of people with polypathology in a hospital setting.

According to these criteria, patients are defined as pluripathological or polypathological when they have chronic diseases which belong to TWO or MORE of the 8 categories outlined in Table 1.

Table 1

**Criteria which define the Polypathological Patient (the patient must present chronic diseases defined in TWO or MORE of the following categories)**

<b>CATEGORY A</b>
Heart failure which, in a clinically stable situation, has been classified as grade II by the NYHA <sup>1</sup> (symptoms associated with everyday physical activity) Ischemic heart disease
<b>CATEGORY B</b>
Vasculitis and systemic autoimmune diseases Chronic renal disease defined by raised creatinine levels (>1.4 mg/dl in men or >1.3 mg/dl in women) or proteinuria <sup>2</sup> , which has lasted for at least 3 months
<b>CATEGORY C</b>
Chronic respiratory disease which, in a clinically stable situation, has been associated with: MRC grade 2 dyspnea <sup>3</sup> (breathlessness at normal walking pace on level ground), or FEV1<65% or SaO <sub>2</sub> ≤ 90%
<b>CATEGORY D</b>
Chronic inflammatory intestinal disease Chronic liver disease with portal hypertension <sup>4</sup>
<b>CATEGORY E</b>
Cerebrovascular accident Neurological disease with permanent motor deficits which cause limitations in basic everyday activities (Barthel Index below 60)

<b>CATEGORY E</b> (continued)
Neurological disease with permanent cognitive deterioration, which is at least moderate (Pfeiffer Scale with 5 or more errors)
<b>CATEGORY F</b>
Symptomatic peripheral arterial disease Diabetes mellitus with proliferative retinopathy or symptomatic neuropathy
<b>CATEGORY G</b>
Chronic anemia as a result of digestive losses or non-secondary blood disease, acquired as a result of curative treatment, with Hgb levels < 10mg/dl in two separate assays performed over 3 months apart Active solid or hematological neoplasia which is not secondary to treatment intended to be curative
<b>CATEGORY H</b>
Chronic osteoarticular disease which by itself causes impairment when performing basic everyday activities (Barthel Index below 60)

- 1 Slight limitation of physical activity. Usual physical activity produces breathlessness, angina, tiredness or palpitations.
- 2 Albumin/Creatinine Index > 300 mg/g, microalbuminuria > 3mg/dl in urine sample or Albumin > 300 mg/day in 24-hour urine sample or > 200 microg/min.
- 3 Inability to keep pace with another person of the same age, walking on level ground, owing to breathing difficulties or the need to stop and rest when walking on the flat at one's own pace.
- 4 Defined on the basis of clinical, analytical, echographical or endoscopic data.

The concept of poly pathology covers a broad clinical spectrum, ranging from patients who, as a result of their disease, are subject to a high risk of disability, to patients who suffer from various chronic diseases with continual symptoms and frequent exacerbations that create a demand for care which, in many cases, do not match traditional services within the healthcare system.

Consequently, the poly pathological patient group is not defined solely by the presence of two or more diseases, but rather by a special clinical susceptibility and frailty which

entails a frequent demand for care at different levels which is difficult to plan and coordinate, as a result of exacerbations and the appearance of subsequent conditions that set the patient along a path of progressive physical and emotional decline, with gradual loss of autonomy and functional capacity. They constitute a group which is particularly predisposed to suffer the deleterious effects of the fragmentation and super-specialization of traditional health systems. We can therefore regard them as sentinels or gauges of the general health of the health system, as well as of its level of internal inter-level coherence.

Polypathology then, as a new syndrome, may define a population of patients who are highly prevalent in society and demonstrate considerable clinical complexity, significant vulnerability, frailty and consumption of resources and high mortality at the level of both primary and hospital care, underscoring the need for integrated and coordinated inter-level care.

In accordance with its Quality and Efficiency Plan, the Andalusian Ministry of Health in Spain designed an organizational process to optimize the care of polyopathologies following strategies of total quality management (Chapter 6). This process, which was developed by a team of internal medicine specialists, family physicians and nurses, focuses on roles, workflows and best clinical practices, all supported by an integrated information system, with the fundamental aim of achieving continuity of care (15, 16).

Recently the incidence of polyopathologies in internal medicine wards of a tertiary-level hospital was estimated at 39% of admissions each month (17). Moreover, this study demonstrated prospectively that the criteria outlined above correctly identified patients with significant clinical complexity and frailty (35% met 3 or more criteria and had a greater need for urgent care and hospital admissions); high mortality (19% during the index admission) and progressive disability (significant impairment and functional deterioration during the care process).

The importance of standardized definitions and processes for the management of polyopathological patients has begun to be reflected in publications about comorbidity at the national level, when referring to both hospitalized patients (17-21) and the general population (22-24).

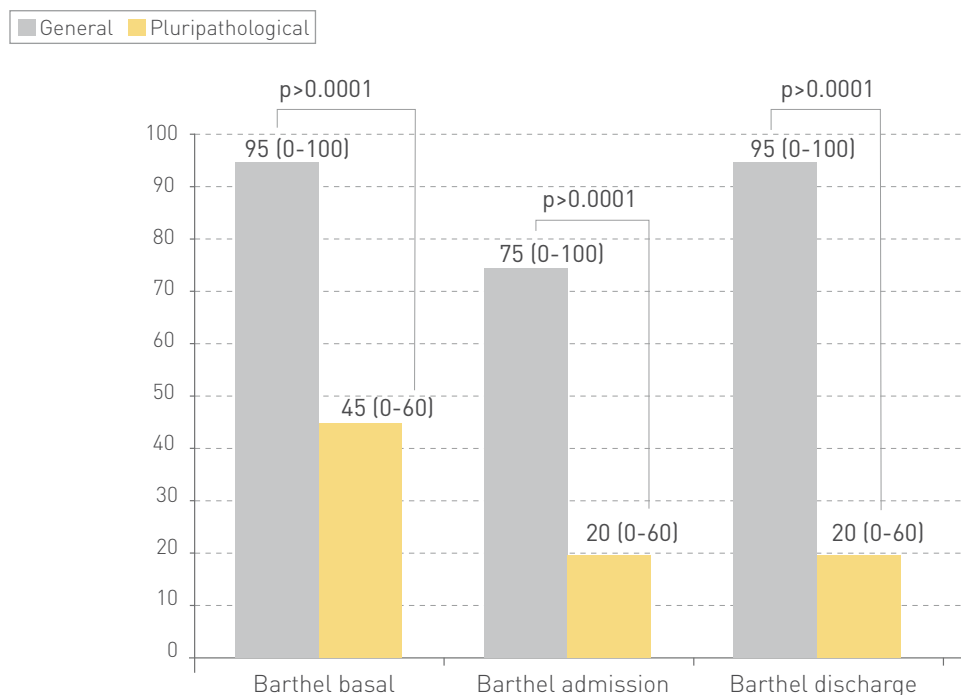
Recently it has been demonstrated that mortality rates amongst hospitalized polyopathological patients are significantly higher during hospitalization than in patients who are not hospitalized, irrespective of the cause of hospitalization. The factors

independently associated with a poorer vital prognosis were more advanced age and a poor functional situation.

Moreover, these patients usually deteriorate more while in hospital than non-polypathological patients. Figure 1 shows the results of a recent comparative study on functional deterioration in the presence of polypathology and general patients during conventional hospitalization (24).

Figure 1

**Baseline Functional Impairment (measured on the Barthel scale) at Admission and Discharge of General and Pluripathological Patient Cohorts**



Source: *García-Morillo JS, Bernabeu-Wittel M, Ollero-Baturone M, Aguilar-Guisad M, Ramírez-Duque N, González de la Puente MA et al. Incidence and clinical features of patients with comorbidity attended in internal medicine areas. Med Clin [Barc]. 2005; 125(1):5-9.*

## Complex chronic disease

Used at institutions that specialize in multiple chronic diseases, such as Bridgepoint Health in Canada, this is another emerging term used in relation to people living with two or more chronic diseases [[http://www.lifechanges.ca/complex\\_chronic/](http://www.lifechanges.ca/complex_chronic/)]. The main limitation of this term, however, is that pluripathology is only one aspect of the complexity in these cases. People living with polypathology may be complex or not, depending on many other related factors. In fact, polypathology may be neither a necessary nor sufficient condition. Some patients might be complex with a single «classical» disease, while others with multiple conditions might be easy to manage with few resources. For instance, a person living on the street with just schizophrenia is complex, while a stable well-controlled person with diabetes with managed hypertension and hyperlipidemia is not.

Therefore, in complex patients the disease burden is not only dependent on the health problems, but also on social, cultural, environmental circumstances and lifestyle. It cannot be denied that these circumstances will frequently exacerbate or alleviate the disease burden, and they may explain the different consequences of identical clinical situations for different people (25).

## Confluent morbidity

Multiple coexistent diseases can be given diagnostic labels that are easily counted and aggregated, for epidemiologic purposes or for the creation of clinical practice guidelines. However, as the number of diseases increases in a person, the clinical value of this approach decreases. An increasing number of diseases is often accompanied by an increasing number of medications. At some point the confluence of the effects of the conditions and the prescribed medications is so complex that it prevents any clear-cut effort to attribute signs or symptoms to a specific cause (26). In these cases, the term confluent morbidity could enable clinicians and patients to focus on the relief of symptoms and not on futile diagnostic exercises.

## Assessment tools

A systematic review of methods to measure comorbidity revealed one that was a simple disease count and 12 indexes (27). The following were regarded as valid and reliable:

## The Charlson Index

This is the most extensively used instrument for prognostic evaluation in patients with comorbidity. It was published initially in 1987 and subsequently modified in 1994. The creation of the Charlson index (28) was initially based on a prospective study of 559 patients that correlated one-year mortality with comorbidity (Table 2). Depending on the cause of mortality, a score was given to each chronic disease present and, when these were added up, the result was an index which correlated well with mortality.

The success of the Charlson index is largely due to the modification introduced by Deyo (29), who adapted to the diagnostic codes stored in administrative databases with information about more than 27,000 patients subjected to lumbar spine interventions in 1985. Deyo's adaptation of the Charlson index has become the most widely used index of comorbidity. It is important to emphasize that the study was based on a hospital cohort and on one-year mortality. The mortality for each study patient quartile was: score 0: 12%; score 1-2: 26%; score 3-4: 52% and score 5: 85%.

The index has subsequently been validated for different geographic areas and different groups of patients with specific pathologies, and it has also been correlated with many variables such as health-related quality of life, readmissions and health costs, among others.





Table 2

**Modified Charlson Index**

<b>PATHOLOGY</b>	<b>SCORE</b>
Coronary disease	1
Congestive heart failure	1
Peripheral vascular disease	1
Cerebrovascular disease	1
Dementia	1
Chronic pulmonary disease	1
Connective tissue disease	1
Peptic ulcer	1
Mild liver disease	1
Diabetes	1
Hemiplegia	2
Moderate-severe renal disease	2
Diabetes with damage to target organs	2
Any tumor, leukemia, lymphoma	2
Moderate-severe liver disease	3
Solid metastatic tumor	6
AIDS	6

In addition, for each decade > 50 years 1 extra point is added.

Source: Deyo RA, Cherkin DC, Ciol MA. Adapting a clinical comorbidity index for use with ICD-9-CM administrative databases. *J Clin Epidemiol.* 1992; 45(6):613-619.

### The CIRS Scale (Chronic Illness Resources Survey)

This tool has been validated in different regions of the world and in very diverse patient populations (30). Its principal advantage is that its scoring scale defines the extent to which organs and systems are affected, without referring to specific diseases (Table 3). Despite its validity and reliability, however, there are few references to its use in research studies.

Table 3

Cumulative Illness Rating Score

ORGAN-SYSTEM	SEVERITY
1. Cardiac	0-1-2-3-4
2. Vascular	0-1-2-3-4
3. Hematological	0-1-2-3-4
4. Respiratory	0-1-2-3-4
5. Ophthalmological and ORL	0-1-2-3-4
6. Upper gastrointestinal	0-1-2-3-4
7. Lower gastrointestinal	0-1-2-3-4
8. Hepatic and pancreatic	0-1-2-3-4
9. Renal	0-1-2-3-4
10. Genito-urinary	0-1-2-3-4
11. Musculoskeletal and cutaneous	0-1-2-3-4
12. Neurological	0-1-2-3-4
13. Endocrine, metabolic, mammary	0-1-2-3-4
14. Psychiatric	0-1-2-3-4

Score, depending on the extent to which the organ/system is affected: 0 Absence of disease; 1 mild; 2 moderate; 3 severe; 4 very severe.

Source: Linn BS, Linn MW, Gurel L. Cumulative illness rating scale. *J Am Geriatr Soc.* 1968; 16(5):622-626.

### The ICED (Index of Coexisting Disease)

This was developed [31] as a tool to assess the prognosis of cancer survivors. It has subsequently been validated for other patient populations with different comorbidities. The main advantage of this prognostic tool is that it combines two dimensions: the severity of the disease, and the level of disability or functional compromise as experienced by the patient.

The first dimension (IDS or individual disease severity) includes a total of 19 possible comorbidities, each of which is scored on a scale that spans from 0 (absence of the disease in question) to 3 (severe disease).

The second dimension assesses the impact of comorbidities on the physical state of the patient (IPI or individual physical impairment). It evaluates 11 physical functions, grading them from 0 (normal function) to 2 (severe disability, dependence in order to perform a particular physical function).

This tool is rarely used, probably because it is too complex to apply in busy clinical settings.

### The Kaplan or Kaplan-Feinstein Index

This was developed to facilitate the prognostic assessment of patients with diabetes in relation to their comorbidity (32). Subsequent attempts have been made to export this instrument to other patient populations, but the results have been highly divergent and its use is therefore now only recommended for health research in diabetic populations (Table 4).



Table 4

**Kaplan-Feinstein Comorbidity Index**

ORGAN, SYSTEM OR CONDITION	SEVERITY
1. Hypertension	0-1-2-3
2. Cardiac system	0-1-2-3
3. Brain or nervous system	0-1-2-3
4. Respiratory system	0-1-2-3
5. Renal system	0-1-2-3
6. Hepatic system	0-1-2-3
7. Gastrointestinal system	0-1-2-3
8. Peripheral vascular system	0-1-2-3
9. Malignant tumor	0-1-2-3
10. Locomotor impairment	0-1-2-3
11. Alcoholism	0-1-2-3
12. Miscellaneous	0-1-2-3

Score, depending on the extent to which organs/systems are affected by disease: 0 = Absence of disease; 1 = mild; 2 = moderate; 3 = serious.

Source: Kaplan MH, Feinstein AR. A critique of methods in reported studies of long-term vascular complications in patients with diabetes mellitus. *Diabetes*. 1973; 22(3):160-174.

## Other instruments

There has been a flurry of activity since the beginning of the new century, with new tools developed and validated with the intention of predicting mortality among pluripathological patients over the age of 70 years, mostly following hospital discharge (33-36). The Spanish Society of Internal Medicine is also supporting a multi-centre project, known as PROFUND, which is aimed at developing a new tool for the assessment of the prognosis of polypathological patients (37).

Other tools have been designed to enable patients to self-report multiple chronic diseases (38-40). Their clinical utility is still unclear.

## What do we need to know?

The following questions aim to encapsulate some of the most important knowledge gaps in relation to the language of polypathology:

- Is it possible to develop a valid, user-friendly and widely acceptable patient-centered tool that could provide a holistic assessment of the experience of people living with multiple chronic diseases? Such a tool (or toolkit) should ideally integrate issues related to symptom burden, functional status, psychosocial support needs and self-rated health. It should also be sensitive to changes over time and equally valuable to clinicians (especially in busy clinical settings), researchers, policy makers, managers and patients.
- Is it feasible to create a globally accepted common language for polypathology, a taxonomy? Such an initiative would be invaluable in facilitating the codification and benchmarking of clinical activities, and in the evaluation of interventions and policies across institutional and geographic boundaries.

## What innovative strategies could fill the gaps?

The development and validation of usable and widely acceptable tools to identify, assess and guide the management and study of polypathologies will only be possible through meaningful global collaboration among leading academic, political, corporate and community organizations. The OPIMEC platform has been equipped with powerful resources to make this possible. It includes a workspace exclusively dedicated to the co-creation of terms related to polypathology, which has been populated with content from what may still be the only taxonomy designed with management issues in mind (41). The space also includes social media resources that enable anyone, anywhere in the world, to make a contribution and to join forces with like-minded people, free of charge (42). The challenge now is to use these resources with the enthusiasm and commitment required to meet the challenge.

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### *Contributors*

Manuel Ollero, Máximo Bernabeu and Manuel Rincón wrote the first draft of this chapter in Spanish.

Alejandro Jadad approved the first draft before it was made available online through the OPIMEC platform. This draft received important contributions from Ross Upshur and Bob Bernstein (in English). Francisco Martos incorporated these contributions into the revised version of the chapter, which was edited extensively and approved by Alejandro Jadad.

Responsibility for the content rests with the main contributors and does not necessarily represent the views of Junta de Andalucía or any other organization participating in this effort.

### *Acknowledgments*

Antonia Herráiz Mallebrera, José Murcia Zaragoza, Isabel Fernández y Barbara Paterson made comments on the chapter (in Spanish) that did not lead to changes in its contents.

### *How to reference*

Ollero M\*, Bernabeu M\*, Rincón M\*, Upshur R, Bernstein B. [\*Main contributors] The language of polyopathy. 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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## Prevention and health promotion

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

### Vignette: How it could be

*It is the year 2020. Carlos is 85 years old. He has diabetes and heart disease, but he still manages to live remarkably well on his own with the support of technology. When he was younger, there was little interest in prevention in his community. Carlos smoked, ate a poor diet and exercised little in adolescence and early adulthood. But for the past 15 years Carlos has placed much more emphasis on prevention, in keeping with the development of a health promoting environment in his community and his country.*

*El Dorado, the community where Carlos lives, has changed dramatically over the past 35 years. It has become a much healthier place to live. Many shops used to sell processed and fast foods, but now it is easier to buy fresh fruit and vegetables. Also the shops in his neighbourhood used to sell cigarettes, and the bars and cafes were full of smoke. Nowadays all public places are smoke-free and it is unusual to see a person smoking. Exercising was difficult in the past because the streets were jammed with traffic. Now traffic congestion has declined and cycling has increased. In fact, Carlos himself cycled up until five years ago.*

*At the national level, the government has also worked hard to develop policies that can reduce social and health disparities in this region. These disparities were some of the main reasons why people in the country were experiencing multiple chronic diseases (e.g. poor housing; poor air quality, food and water; and children not having a healthy start in life).*

*From the age of 60 onwards, Carlos was regularly screened for risk of heart disease and stroke, abdominal aortic aneurysm (ballooning of the main artery from the heart), bowel cancer, diabetic eye disease and high blood pressure. The screening results indicated that he was at high risk of heart disease and stroke and at age 50, in addition to improving his health behavior, he began taking*

*a polypill (a pill which contains drugs that lower blood pressure and blood lipids, and the likelihood of blood clotting).*

*The local community health services have also become much more geared towards people with multiple health issues. From the age of 60, Carlos was contacted regularly by a community health worker. From the age of 70 onwards he was visited by a nurse, who came more often if he was having problems. Since then, advances in technology have enabled him to send regular reports on the various tests he has self-administered and a nurse has contacted him if necessary. He also has a community health worker, who often comes to offer emotional and social support, to help him and to keep him cheerful and hopeful. The combination of the nurse, the community health worker and technology, used in a coordinated way, has allowed him to stay at home, despite being very limited in what he can do. Carlos's family is engaged in helping to manage his health and they are supported by the health and social care system to ensure he keeps as healthy as possible.*

*Creating the conditions that have helped Carlos to stay healthy, despite his limitations, and to live at home, has depended, to a large extent, on the building of a culture of health in his community and on the efforts of local planners and authorities, and health service managers. Many of the services he is entitled to are provided in a cost-effective manner, which is achieved by ensuring that health professionals use their practical abilities to the full and that care is coordinated, and by providing the appropriate skill mix which is needed for optimal health outcomes.*

## Summary

- It is important to understand the health trajectory and life conditions that result in multiple co-morbidity and complex chronic disease in order to determine the most effective individual and populational approaches to prevention.
- Prevention can be categorised in the following four ways, which may provide a useful framework for thinking about prevention and polyopathy: primordial, primary, secondary and tertiary prevention.
- Three preventable risk factors contribute to a large extent to chronic disease: tobacco use, poor diet and physical inactivity. These risk factors need to be addressed at all levels of society, from governments to the individual, paying particular attention to populations which are at the highest risk of developing chronic disease.
- All individuals should be encouraged and supported by their communities to avoid smoking, eat a healthy diet and exercise regularly. In some cases there may be a level of risk where drug treatment is justified.

- One radical and controversial strategy for preventing heart attacks and strokes is for everybody at the age of 55 to start taking a single pill, which combines drugs that lower blood pressure and blood lipids, and the likelihood of blood clotting (known as a polypill).
- Screening populations for early signs of disease can play an important role in prevention, but it is important that a number of criteria are met, including the use of a reliable test, effective treatment, the possibility of early detection of pathology long before serious disease manifests itself and cost effectiveness.
- Guidelines are increasingly used for managing patients with chronic conditions, but they are usually designed for treating patients with single conditions. Combining guidelines designed for patients with single conditions to treat patients with multiple conditions may be not only ineffective but also dangerous.
- Information and communication technologies, particularly those which promote tele-monitoring and tele-consultations, have been conclusively shown to improve outcomes for patients with chronic conditions and to lower costs, mainly by reducing hospital admissions.

## Why is this topic important?

Clearly when patients with complex chronic conditions are so common and they experience so many complications and inappropriate hospital admissions, prevention and health promotion are important.

Prevention within the context of polypathology, however, should be about creating the conditions for patients that will avoid them developing further disorders and prevent them from presenting complications of existing pathologies. Many of these patients will be elderly and approaching the end of their lives as well as having coexisting psychological and social problems. Indeed, their personal, family and social concerns may have little to do with their diseases and it is essential that preventive care should be person centred, not disease centred. For example, it may be inappropriate to press as hard to stop such a patient smoking, as would be the case for a younger person, if the elderly patient places a high value on smoking.

Policy makers will be very interested in prevention and polypathology because small percentage reductions in hospital admissions and complication rates can translate into

considerable savings, which is important for the whole healthcare system. All stakeholder groups should be interested in prevention and health promotion in polypathology because we know a lot about the prevention of individual chronic conditions, but little about prevention and health promotion amongst people with complex chronic conditions. Yet, as we have been describing, these patients account for much of the work and cost for the healthcare system.

## What do we know?

Despite the size of this chapter, there is very little evidence of the best approaches for the prevention of polypathology, as we are still at the stage where we are getting to grips with understanding this population and the determinants that contribute to it.

One useful way to think about prevention is to divide it into primordial, primary, secondary and tertiary prevention and to consider these different levels in the context of Complex Chronic Disease (CCD). The following definitions of these terms are taken from the WHO's book on basic epidemiology (1).

Primordial prevention is concerned with creating economic, environmental and social conditions that are conducive to health and that minimise the likelihood of developing disease. An example would be reducing poverty. Heart disease and stroke are often more common among poorer people.

Primary prevention addresses specific causal factors, like tobacco use, poor diet and physical inactivity in the case of chronic disease, in order to reduce the chances of people developing disease. Examples include raising taxes to reduce tobacco consumption and providing smoking cessation programmes. Another example would be policies designed to reduce the salt content of processed food.

Secondary prevention is concerned with targeting people with a disease which is established but usually at an early stage, in order to limit the exacerbation of the disease and the development of complications. An example would be treating diabetic patients to control their blood sugar and hypertension to minimise and delay such complications.

Tertiary prevention is concerned with patients with well-established disease and its aim is to minimise suffering and complications. Tertiary prevention is akin to treatment and rehabilitation and is perhaps most directly relevant to patients with complex chronic disease. An example of tertiary prevention would be a disease management programme,

where case managers follow patients, perhaps by phone, and prompt them to take preventive treatments and attend for screening.

Dividing prevention into these categories is no more than a device for thinking about polypathology and the different levels frequently merge and overlap. The Australians have a phrase: «healthy planet, healthy places, healthy people» that expresses how these levels overlap (2). It is very difficult for individuals to be healthy if they live in unhealthy places where, for example, the water and air are polluted, smoking is common, high fat and high salt foods are readily available when fruit and vegetables are not, and where it is hard to find space to exercise. And, as the whole planet becomes unhealthy through climate change, pollution and urbanisation, so it becomes increasingly difficult to create healthy places.

This chapter will discuss all the prevention categories, except tertiary prevention, which will be covered elsewhere in Chapter 6.

## Primordial and Primary Prevention

### Social Determinants of Chronic Disease

The social, environmental and economic circumstances of people's lives are central to determining their health and chances of developing chronic disease. Life expectancy varies by as much as 40 years between countries and by more than 10 years within countries. Income, education, housing, employment, social networks and many other factors are all influential and intertwined, as the WHO has recognised in its crucial report on the social determinants of health (3). Access to health care is also a social determinant of health. Any strategy designed to reduce chronic disease must recognise the importance of these social determinants and strategies that ignore them will have only limited impact.

Chronic disease has three main preventable causes: tobacco use, poor diet (including excessive alcohol consumption) and physical inactivity. The discussion that follows is an exploration of what we know about reducing tobacco consumption, and promoting healthy eating and physical activity.

## Tobacco Consumption

Tobacco consumption kills five million people a year globally and that number is set to rise to eight to 10 million by 2030 (4). Half of all smokers die prematurely as a result of smoking and yet, if people stop smoking, they can return to having the same risk as non-smokers within 10 to 15 years.

The world has largely recognised the extreme dangers that tobacco poses and, consequently, the WHO, for instance, has created the Framework Convention on Tobacco Control, which commits countries to regulating tobacco sales, reducing consumer demand for tobacco, improving the environment and health of tobacco workers, and encouraging research. A total of 168 countries out of a possible 192 have signed the convention, the United States and Indonesia being the largest countries not to follow suit.

We know a great deal about public health measures that are effective in reducing tobacco consumption. The WHO has put together the MPOWER package of six policies which are known to be effective (4).

They include the following:

- 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.

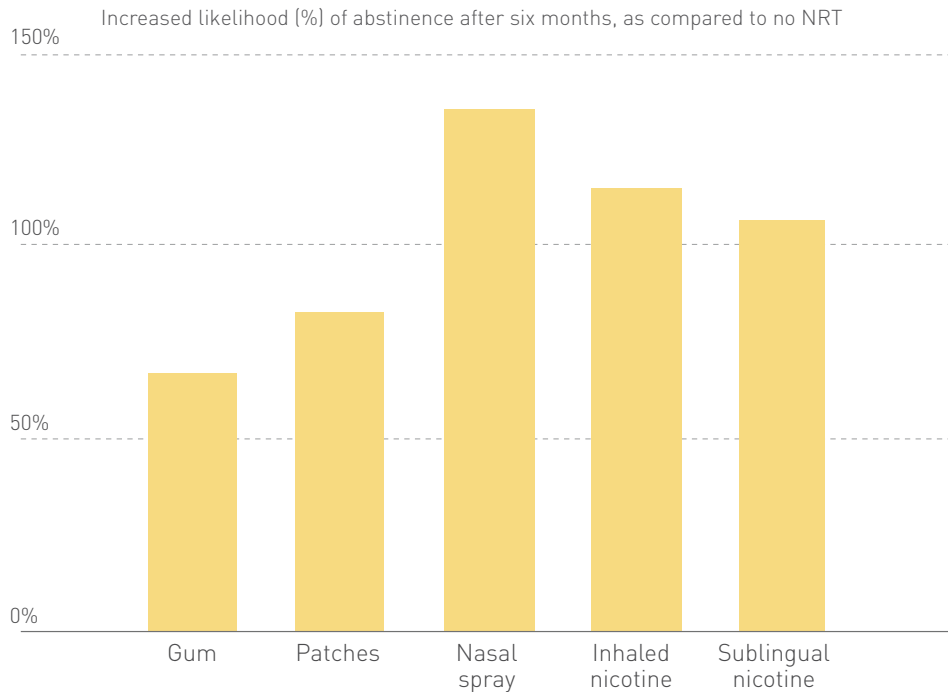
We need to support research in a number of areas: tobacco control, surveys of smoking levels, global cigarette consumption, the economic effects on individual countries (tobacco leads to losses not gains, as the costs of damage outweigh income from taxation), smoking costs to employers, economic costs of fires and litter, costs to smokers, tobacco company documents, litigation, the tobacco industry and the recruitment of scientists to the tobacco company cause.

Banning smoking in workplaces and public places, and increasing taxes on tobacco, are two of the most effective interventions (4).



Figure 1

### Effectiveness of Various Forms of Nicotine Replacement Therapy in Helping People to Stop Smoking



Source: Silagy C, Lancaster T, Stead L, Mant D, Fowler G, «Nicotine replacement therapy for smoking cessation», *Cochrane Database System Review 2004; (3); CD000146.*

Figure 1 shows data from a Cochrane Review on smoking cessation rates after various forms of nicotine replacement therapy (4, 5). The vast majority (between two thirds to three quarters) of ex-smokers stop smoking completely with no assistance (6, 7). This data comes from nations which have experienced two decades of major promotion of nicotine replacement therapy, using budgets that dwarf public campaign expenditure on smoking cessation.

Most smokers (by far) quit after being exposed to mass-reach policies, campaigns and the changing culture of smoking. They do not use drugs, go to counselling or even phone quitlines. This is an important and very positive message.

Nearly all the trials on nicotine replacement therapy have been conducted in wealthy countries. These nations differ substantially from low and middle-income countries in their culture of smoking control (smoking is far more accepted in most low and middle-income countries; there is scant tobacco control in most of them, including few motivational campaigns urging cessation). It is unwise to assume a similar interest, on the part of the population, in nicotine replacement therapy in the countries where most of today's smokers live.

Countries that have implemented comprehensive bans on advertising (meaning bans on media and point-of-sale advertising) have seen much greater falls in tobacco consumption than countries that have not introduced such bans (4, 8). There are clearly issues around causation here, but the evidence on the effectiveness of comprehensive bans is strong. Reducing taxes on tobacco leads to higher consumption and raising them reduces consumption (4, 9). This sensitivity to price has been seen repeatedly in many countries at different times and is well established.

Much of the evidence on reducing the harm tobacco causes concentrates on cigarettes, but in many regions of the world, such as South Asia, other forms of smoked tobacco like bidis and smokeless, oral tobacco consumption are common, particularly among women and young people.

What we know much less about is the effect of these policies, including nicotine replacement therapy, in patients with complex chronic conditions. Indeed, of some 40 Cochrane reviews on smoking cessation none involve patients with established chronic disease. Often a whole range of trials exclude or control for polyopathy.

It is also important to acknowledge that the control of tobacco use is made much more difficult by the presence of a powerful tobacco industry which is focused on promoting tobacco sales worldwide. These companies are increasingly concentrating their energies on low and middle-income countries, where the number of smokers and potential smokers is substantial and controls may be weak. These countries often depend on tobacco for economic development.

## Diet and Physical Activity

The goal of tobacco reduction is very clear: to reduce its use as much as possible in individuals and populations, and ideally to create a smoke-free world. The aim with respect to diet and physical activity is less clear and there continues to be intense debate over what should be recommended in both cases; the same applies to determining what actions will produce the greatest benefit, for whom and under what conditions.

The WHO recommends the following guidelines for individuals who wish to improve their diet (10):

- Achieve energy balance and a healthy weight.
- Limit energy intake from total fats and shift fat consumption from saturated fats to unsaturated fats and towards the elimination of trans-fatty acids.
- Increase consumption of fruits and vegetables, and legumes, whole grains and nuts.
- Limit the intake of free sugars.
- Limit salt consumption from all sources and ensure that salt is iodised.

With respect to physical activity, the WHO recommends «at least 30 minutes of regular, moderate-intensity physical activity on most days» (10).

This level of activity is expected to reduce the risk of cardiovascular disease, diabetes, colon cancer and breast cancer. More activity may be required for weight control. A recent Cochrane review of 43 randomised trials with 3,476 participants found that exercise increased weight loss compared with no treatment, but dieting was more effective (11).

Exercisers lost 0.5 to 4.0 kg, whereas subjects randomized to no treatment groups gained 0.7 kg or lost 0.1 kg. Exercise had more effect on risk factors for heart disease than on weight and more intense exercise led to more weight loss. The effects of exercise seem to be different in men and women, with women needing to reduce their calorie intake more actively to lose weight (12). Many people with multiple chronic conditions will not be able to exercise for 30 minutes on most days, although, counter to general opinion, the Diabetes Prevention Program showed that people aged 60 or older were more likely than younger people to follow advice to exercise more and improve their diet (13).

Increasing physical activity may be more beneficial than improving diet in that, as well as reducing the chance of developing chronic disease, it also improves quality of life, which may be particularly important in people with complex chronic disease (14).

The WHO recently completed a systematic review of the evidence as to what works in increasing physical activity and improving diet (15). It examined the evidence using the following categories: policy and environment, mass media, school settings, workplace, community, primary health care, older adults and religious settings (Table 1).

Table 1

**A Systematic Review of Interventions Designed to Improve the Diet and Promote Physical Activity (15)**

CATEGORY	Total number of peer-reviewed studies	Total number of interventions	Interventions focused on disadvantaged communities	Interventions in low or middle-income countries
Policy and environment	30	23	3	2
Mass media	36	24	2	3
School settings	107	55	14	1
Workplace	49	38	5	1
Community	75	65	22	3
Primary health care	67	29	5	0
Older adults	18	17	3	3
Religious settings	13	10	10	0
<b>Total</b>	<b>395</b>	<b>261</b>	<b>64</b>	<b>13</b>

The reviewers identified 395 studies that met their inclusion criteria, but only 13 were related to low or middle-income countries and only 18 were concerned with older adults. The review considered psychosocial, behavioural and clinical outcomes and classified interventions as effective, moderately effective, promising but based on limited evidence, minimally effective, based on insufficient evidence or not shown to be effective, or with outcomes which were not measured or reported. Taking into consideration the limitations of the studies that were included in the analysis, the main findings of the review are summarized as follows:

- **Policy and environment:** Three interventions were found to be effective:
  - 1) government regulation that supports healthier staple foods; for example, replacing palm oil with soya oil, thus reducing dietary fatty acid content; 2) building, planning and transport policies that reduce the barriers to physical activity; and 3) point of decision prompts that encourage the use of stairs. Moderately effective interventions include pricing policies, point of purchase prompts to support healthier choices and multi-targeted approaches to encourage more walking and cycling.
- **Mass media:** Campaigns to encourage physical activity are effective if they are combined with community based support programmes or associated with policies to reduce environmental barriers to physical activity. Moderately effective interventions include intensive campaigns that concentrate on one simple message (like increasing consumption of low fat milk), national health brands or logos that signal healthier foods to consumers and long-term, intensive campaigns that promote healthy diets.
- **School settings:** High intensity school programmes can work if they are comprehensive and have many components, including teaching provided by trained individuals, supportive school policies, a physical activity programme, a parental/family component and access to healthy food options in schools. Focused programmes and assessments of the needs of schools and their cultural context are moderately effective.
- **Workplace:** Multi-component workplace programmes that include the provision of healthy foods and space for exercise, involving the staff in planning and implementation, incorporating family interventions and helping individuals to change, and monitoring, are effective.

- **Community:** Three interventions have been shown to be effective in the community. Firstly, multi-component diet education programmes that target high-risk groups. Secondly, community development programmes that either involve intersectorial cooperation or have a single goal, for example, reducing the risk of a cardiovascular event. Thirdly, community-based programmes for a homogenous group. Several interventions have been shown to be moderately effective: using existing phone-in services to provide dietary advice; community interventions performed as part of a national or global campaign; programmes that target the poor or illiterate and include dietary advice; computer-based interventions that provide personalised feedback to high-risk groups; supermarket tours to support the purchase of healthier foods; and walking school buses.
- **Primary care:** Primary care interventions that target individuals at risk of chronic disease can be effective if they include people who are inactive, eat less than five portions of fruit or vegetables a day, consume a lot of fat, are overweight or have a family history of chronic disease; if they include at least one session with a health professional who negotiates reasonable goals with follow-up provided by trained staff; and if they are supported by targeted information. Interventions which are linked with actions taken by other stakeholders, for example, sports organisations or the mass media, can also be effective. Programmes that identify patients with raised blood cholesterol levels and provide follow-up are moderately effective, as are weight loss programmes that include telephone or internet consultations over a period of at least four weeks and a self-help programme with self-monitoring.
- **Older adults:** Although the systematic review found 18 studies of 17 interventions in older adults, it did not identify any effective interventions in this particular age group, which is very relevant to our focus on people with multiple chronic conditions. Moderately effective interventions included those encouraging physical activity in a group setting that used an existing social structure or meeting place, and home-based interventions in which older adults are given increased access to fruit and vegetables using an existing infrastructure.
- **Religious settings:** Culturally appropriate and multi-component dietary interventions, which are planned and implemented in conjunction with religious leaders and include group education sessions and self-help strategies, are effective. Culturally appropriate interventions that target weight loss, healthy diets and increased physical activity are moderately effective.

This review identifies many interventions in which there is evidence to show that they are effective and then notes characteristics that seem to be shared by interventions that work. These tend to be: multi-component in design, adapted to the local context culturally and environmentally, appropriate use, existing social structures and involving participation by stakeholders throughout the process.

The authors of the review also note that most of the studies are short-term, meaning that most of the outcomes are psychosocial rather than clinical and that we have little evidence about programme sustainability. Few of the studies provided evidence about cost effectiveness or examined unintended consequences.

The limited evidence from low and middle-income countries makes it clear that involving communities in all stages of planning, implementation and evaluation is important for success.

With respect to polypathologies, there is a real need for a review that takes these concepts and approaches and examines their relevance to prevention, as well as the trajectory that leads to polypathology. If X practices and policies were in place, could we reduce the incidence of CCD and delay its onset and impact? What populations are at the highest risk for CCD? Should we focus on high-risk populations in terms of population health intervention and policy? What efforts are required to effect change in these populations? What analyses are required?

A comprehensive analysis of neighbourhoods and diabetes in Toronto, Canada (ICES, 2007) provides very valuable insights into the social and physical context as a determinant of chronic illness and who is most at risk, and into approaches that may be useful in reducing its incidence. This research is a good example of new approaches to studying polypathology and its prevention (16).

## Primary Prevention: Treating Populations or Individuals?

Primordial prevention focuses on population health, but, once we move to primary prevention, then individuals and their families can be targetted. Most health workers in contemporary society are concerned with treating individuals and their families.

People with established disease are at high risk by definition, but risk can also be measured in people who have no established disease. There is controversy over how best to measure risk and at what level to treat people. The WHO recommends measuring cardiovascular risk by using charts that combine risk factors including age, smoking

status, whether or not people have diabetes and systolic blood pressure (17). Charts for well resourced countries also include blood cholesterol levels, but there are charts that exclude cholesterol for places where it is impossible or prohibitively expensive to access laboratories to measure cholesterol. The point of using these charts is that they give a much more accurate estimate of risk than using any one factor alone, although some argue that age is such a powerful determinant of risk that it can be used alone (Nick Wald, personal communication; publication pending).

These charts are developed using data from the famous studies in Framingham in the USA, where a large population was followed up for years. Some experts argue that it is inadequate to use the Framingham data for other countries, where the makeup of the population may be very different. The United Kingdom, for example, which probably has a population which is less different from that of Framingham than many other countries, has used electronic records to generate a new risk assessment tool called QRISK, which has been shown to be a better predictor for the UK than the Framingham tool (18, 19).

Figure 2

**Overlap among Women and Men who will Experience a Cardiovascular Event in the next 10 Years and who are Predicted to Do so by the QRISK and Framingham Risk Assessments**

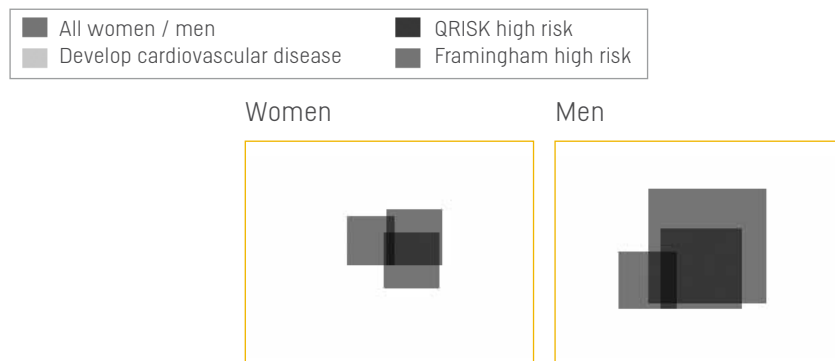


Figure 2 shows, however, that neither tool is very good at measuring risk at the population level. QRISK identifies 10% of men as «high risk» (having a 20% chance of having a cardiovascular event within the next 10 years) but only 30% of cardiovascular events will occur in those men (18). In other words, 70% of cardiovascular events will occur in men defined as being at low risk because they make up 90% of the population.



For women it is worse: QRISK identifies 4% of women as being at high risk, but only 18% of cardiovascular events occur in this group (19).

The WHO recommends lifestyle improvements for people at all levels of risk, as well as regular monitoring for those with a 10-20% risk, and pharmacological treatment for patients with a risk above 20%. The National Institute of Health and Clinical Excellence in England and Wales recommends the same measures (20). The American Heart Association recommends low dose aspirin for patients who have more than a 10% chance of a major cardiovascular event in the next 10 years (21). A recent systematic review suggests that this advice may be misguided (22).

But there is an argument that a 20% chance of a cardiovascular event in the next 10 years is an unacceptably high risk of something that might well result in death or severe disability. People spend large amounts of money every year to insure their houses, which pose nothing like a 20% chance of being burnt down or suffering severe damage in the next 10 years. The risk of potential harm must, of course, be measured against the risk carried by treatment and that is why the authors of the recent systematic review argued against the use of aspirin in people at low risk (22): aspirin will undoubtedly reduce the chances of a thrombosis leading to a heart attack or stroke, but it also increases the risk of a gastrointestinal or cerebral bleed, with the risk of treatment cancelling out any potential benefit.

## The Polypill

But supposing there were a treatment that posed a much lower risk, then it might be reasonable for people to take it, if they had a lower risk of experiencing a major cardiovascular event. Such a treatment could also reduce the overall numbers of heart attacks and stroke because many more people who would have had heart attacks or strokes would be treated. Giving up smoking, losing weight, exercising more and eating a healthier diet will all reduce the chances of a heart attack or stroke and do not carry risks, but slow progress is being made with these measures. Indeed, a cynic might say that, while a relatively small number of relatively wealthy people in developed countries are improving their lifestyle, we have a global pandemic of smoking and obesity.

This is the thinking behind the idea of the polypill, a single pill that contains several drugs (anti-hypertensives, a statin, and possibly aspirin and folic acid). The idea was developed by several researchers around the turn of the millennium but really took off with the publication of papers in the BMJ in 2003 (22). Nick Wald and Malcolm Law used

extensive data to argue that, if everybody aged 55 started routinely taking a pill containing a statin, aspirin, folic acid and three anti-hypertensives at low doses (to get 80% of their benefits with only 20% of the side effects), then 80% of heart attacks and strokes would be prevented. Recent studies have questioned the use of aspirin in the polypill and the version currently advocated by Wald and Law does not include it [21]. The inclusion of folic acid has always been controversial and other polypills do not include it. People at the age of 55 have a risk of about 8% of suffering a major cardiovascular event in the next 10 years simply because of their age. The argument of Wald and Law was that the simplicity of everybody being treated with a single pill would save many more lives than the inherent complexity of assessing risk in individuals and tailoring their treatments using different drugs.

Importantly, because these drugs are no longer subject to patents, the pill might be made for as little as \$1 a month, meaning that treatment might be available to millions in poorer countries, who are at high risk but unable to afford the expense of more traditional treatment. Doctors would not be needed to prescribe the treatment. It could be advocated and dispensed by community health workers.

Some experts welcomed this revolutionary idea with enthusiasm, but many were appalled. For cardiologists the idea promoted inferior treatment, although they acknowledged that most people who will develop heart attacks or strokes are not currently treated because they are not at a high enough risk, are not treated even when they are at risk, are inadequately treated or fail to take their medication. Public health practitioners thought that the polypill would mean that people would not bother to adopt healthy lifestyles. Drug companies saw the potential disappearance of lucrative markets and many found the idea of «medicalising» everybody over 55 years of age offensive.

Although progress has been horribly slow from the point of view of the enthusiasts, the idea of the polypill is gathering momentum and several polypills are now available, most of them manufactured in India. A feasibility trial from India has shown that it is possible to manufacture a pill with all the necessary components, that people will take it and that it will reduce risk factors, although perhaps not enough to reduce heart attacks and strokes by 80% [23].

Some people in India are taking the pill and it may be the case that versions of the polypill will be allowed onto the market in Europe and the USA for secondary prevention. Indeed, there is strong evidence that people who have had heart attacks or strokes should take these pills, although there is also sound evidence that many people are not taking them [24]. A trial to evaluate the effectiveness of the polypill in primary prevention is now being

planned, but it is unlikely to identify the potentially adverse behavioural effects feared by its dissenters (e.g., would those who take the pill feel protected and increase high-risk activities?).

An interesting sideline to this is that combining drugs in one pill may be effective in different circumstances, particularly for people living with multiple chronic diseases, for example, for treating asthma, chronic obstructive lung disease and depression, all at the same time. Polypharmacy has acquired a bad name because it is often an irrational approach, but rational polypharmacy with a number of drugs in one pill may be a much better way forward than spending hundreds of millions to invent new ones that often have only marginal benefits.

## Secondary Prevention

Secondary prevention is concerned with people with established disease, although usually it is at an early stage. Its aim is to limit the extension of the disease and the development of complications. For it to be successful there must be an early stage in the disease that can be identified and an effective treatment for preventing its progression.

Screening, using large-scale tests to identify disease in apparently healthy people, is a form of secondary prevention. Screening for cervical cancer is a good example, as it identifies cancer at an early stage and surgery can remove it. Interestingly, there is now a vaccine against the human papilloma virus, the cause of many cases of cervical cancer, which means that cervical cancer can be prevented through primary rather than secondary prevention, although its use remains controversial.

Perhaps there has been a substantial increase in the demand for screening to ensure the early detection of certain disease conditions because of the well-known phrase «prevention is better than cure». It is necessary, however, to establish the cost-benefit profile of these procedures at the populational level in order to determine the cost for each life which is saved.

Rational screening means that many criteria must be met before mass screening can be introduced and these criteria are shown in table 2. The test itself must be sensitive (good at picking up people with the disease) and specific (unlikely to identify, wrongly, people without the disease as having it). Unfortunately, many potential screening tests have low sensitivity and specificity, meaning that they fail to pick up people with the disease (false negatives) and wrongly identify people who do not have a specific disease as having it (false positives).

Table 2

Requirements for an Effective Screening Programme

Disorder	Well-defined
Prevalence	Known
Natural history	Long period between first signs and overt disease: medically important disorder for which there is effective remedy
Test choice	Simple and safe
Test performance	Distributions of test values in affected and unaffected individuals known
Financial	Cost-effective
Facilities	Available or easily provided
Acceptability	Procedures following a positive result are generally agreed upon and acceptable to both the screening authorities and to those screened
Equity	Equity of access to screening services: effective, acceptable and safe treatment available

Randomised clinical trials are very useful for determining the effectiveness of screening on the mortality and morbidity of specific conditions in populations, particularly in situations where an intervention has been designed to manage the disease on the basis of screening results. Such trials have been conducted to determine the cost of breast cancer screening and systematic reviews show that screening does reduce mortality, despite many women having biopsies of breast lumps that turn out not to be malignant (26).

The cost per quality-adjusted life year (QALY) is about £5,000 in the UK, which is well below the cut-off point of £20,000 to £30,000 used by the National Institute for Health

and Clinical Excellence to decide which interventions should be available as part of the UK National Health Service. [A quality-adjusted life year is a year of life adjusted for its quality or its value; it is a measurement devised by health economists. A year of perfect health is considered to be equivalent to 1.0 QALY. The value of a year of ill health would be discounted. For example, a year in which a person is bedridden might have a value equivalent to 0.5 QALY (26).

It is crucial for any screening programme which is introduced to have a high level of quality assurance. Otherwise it may not achieve its desired results. For years in Britain, for example, cervical screening was not quality assured. The wrong women were screened, the samples were poorly collected and smear reading was not quality controlled. The result was that, before quality assurance was introduced, cervical screening achieved little (28).

Table 3

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**UK Criteria for Appraising the Viability, Effectiveness and Appropriateness of a Screening Programme (updated June 2009)**

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Ideally all the following criteria should be met before screening for a condition is initiated:
<b>THE CONDITION</b>
1. The condition should be an important health problem
2. The epidemiology and natural history of the condition, including its development from latent to declared disease, should be adequately understood and there should be a detectable risk factor, disease marker, latent period or early symptomatic stage
3. All the cost-effective primary prevention interventions should have been implemented as far as this is practicable
4. If the carriers of a mutation are identified as a result of screening, the natural history of people with this status should be understood, including the psychological implications
<b>THE TEST</b>
5. There should be a simple, safe, precise and validated screening test
6. The distribution of test values in the target population should be known and a suitable cut-off level should be defined and agreed

<b>THE TEST (continued)</b>
7. The test should be acceptable to the population
8. There should be an agreed policy on the further diagnostic investigation of individuals with a positive test result and on the choices available to these individuals
9. If the test is for mutations and if all possible mutations are not being tested, the criteria used to select the subset of mutations to be covered by screening should be clearly set out
<b>THE TREATMENT</b>
10. There should be an effective treatment or intervention for patients identified through early detection, with evidence of early treatment leading to better outcomes than late treatment
11. There should be agreed evidence based policies to decide which individuals should be offered treatment and the appropriate treatment to be offered
12. Clinical management of the condition and patient outcomes should be optimised by all health care providers prior to participation in a screening programme
<b>THE SCREENING PROGRAMME</b>
13. There should be evidence from high quality Randomised Controlled Trials that the screening programme is effective in reducing mortality or morbidity. Where screening is aimed solely at providing information to allow the person being screened to make an «informed choice» (e.g. Down's syndrome, cystic fibrosis carrier screening), there must be evidence from high quality trials that the test accurately measures risk. The information that is provided about the test and its outcome must be of value and readily understood by the individual being screened
14. There should be evidence that the complete screening programme (test, diagnostic procedures, treatment/ intervention) is clinically, socially and ethically acceptable to health professionals and the public
15. The benefit from the screening programme should outweigh the physical and psychological harm (caused by the test, diagnostic procedures and treatment)

THE SCREENING PROGRAMME (continued)
16. The cost of the screening programme (including testing, diagnosis and treatment, administration, training and quality assurance) should be economically balanced with respect to expenditure on medical care as a whole (i.e. value for money). The assessment of this criterion should take into account the evidence from cost-benefit and/or cost-effectiveness analyses and consider the effective use of available resources
17. All other options for managing the condition should have been considered (e.g. improving treatment, providing other services) in order to ensure that no more cost-effective intervention could be introduced or that current interventions cannot be increased using the resources which are available
18. There should be a plan for managing and monitoring the screening programme and an agreed set of quality assurance standards
19. Adequate staffing and facilities for testing, diagnosis, treatment and programme management should be available prior to initiating the screening programme
20. Evidence based information, explaining the consequences of testing, investigation and treatment, should be made available to potential participants to assist them in making an informed choice
21. Public pressure to broaden the eligibility criteria, to reduce the screening interval and to increase the sensitivity of the testing process should be anticipated. Decisions about these parameters should be scientifically justifiable to the public
22. If screening is for a mutation, the programme should be acceptable to people identified as carriers and to other family members

Table 3 shows the criteria used by the UK National Screening Programme to decide which screening programmes to introduce. Screening programmes that have met these criteria include screening for abdominal aortic aneurysm, breast, bowel and cervical cancer, diabetic retinopathy, hypertension and vascular risk. Table 4 shows the programmes which have not met the criteria, often despite popular for them to be introduced.

Table 4

**Systematic Population Screening Programmes which have not been Recommended in the UK**

Alcohol problems	Glaucoma
Alzheimer's disease	Glomerulonephritis
Atrial fibrillation	Haemochromatosis
Cancers: Anal   Bladder   Lung   Oral   Ovarian   Prostate   Stomach   Testicular	Hearing loss
Chlamydia	Hepatitis C
Coeliac disease	Old age
Chronic kidney disease	Osteoporosis
Depression	Postnatal depression
Diabetes	Stroke
Domestic violence	Thrombophilia
Familial hypercholesterolaemia	Thyroid disease



Many disadvantaged populations, for example, people with learning disabilities or chronic mental health problems, are less likely to be screened. This may well be true as well for people with multiple chronic conditions.

Measures to stop people smoking, increase physical activity and improve diet will also be effective as secondary preventive strategies in patients with established cardiovascular disease, but patients also need pharmacological treatments to reduce the chances of recurrence or of complications in the case of diabetes or progression of chronic respiratory disease. Most of these treatments are firmly based on evidence, although there have recently been interesting suggestions from a major trial that tight control of blood sugar in diabetic patients may lead to worse outcomes [29].

## Joining up all the Pieces

Although we have followed the classic epidemiological division of levels of prevention, governments and health authorities must decide on the right mix for their particular circumstances. Some governments will have very few resources for health systems and so may concentrate on social determinants of health. Other governments may operate in political environments where any form of «social engineering» is suspect and so they may concentrate on strategies targetted at sick individuals.

## What do we need to know?

### General

- What are the health trajectories and life conditions that result in multiple co-morbidity and complex chronic disease?
- What are the most effective individual and populational approaches to prevention?
- What are the approaches in terms of conceptualizing prevention in the chronic disease literature that can be applied to poly pathology?
- What is new or different about the poly pathological population?
- What research questions is it important for us to pursue?
- What is the relative contribution of primordial, primary, secondary and tertiary prevention in improving outcomes and satisfaction, and reducing costs in people

living with multiple diseases? What is the best prevention strategy to pursue in any given set of circumstances? Can we produce a guide that could be used in very different circumstances?

The following is a list of research and policy questions for primordial, primary and secondary prevention.

## Primordial and Primary Prevention

- How could healthier communities be promoted, particularly in low to middle-income countries?
- What would motivate more countries, particularly the United States and Indonesia, to sign the Framework Convention on Tobacco Control?
- Is it possible to monitor, by country, research into tobacco control, surveys of smoking levels, global cigarette consumption, the economic effects on individual countries (tobacco leads to losses not gains as the costs of damage outweigh income from taxation), smoking costs to employers, the economic costs of fires and litter, costs to smokers, tobacco company documents, litigation, the tobacco industry and the recruitment of scientists to the tobacco company cause?
- What are the effects of MPOWER policies, particularly nicotine replacement therapy, on people living with multiple chronic diseases?
- What is the optimal diet and level of physical activity for people with multiple chronic conditions? How sustainable, cost-effective and safe are effective interventions?
- Which policies to improve diet and increase physical activity will be effective in patients with multiple chronic conditions?
- How might people in low and middle-income countries, who currently have healthy diets, be encouraged to keep to them rather than switch to unhealthy high fat, high salt, high calorie diets?
- How can we ensure that, with increasing urbanisation and urban poverty, the inhabitants of cities in low and middle-income countries are able to sustain levels of physical activity?
- How best to measure the risk of developing cardiovascular disease, particularly in places where laboratory tests are unavailable or unaffordable?

- Might age alone be used for risk assessment; if so, would the cut-off point be different in different countries?
- What is the right level of risk at which to begin pharmacological treatment?
- Will the polypill be more cost-effective than routine treatment in primary, secondary and tertiary prevention?
- What should the components of the polypill be?
- What is the best strategy for using the polypill in primary prevention: risk assessment followed by treatment or to offer the polypill to everyone above a certain age?
- If the polypill is cost-effective, how can its widespread use be encouraged?
- Might other polypills be useful in other forms of prevention, for example, smoking cessation or chronic lung disease?

## Secondary Prevention

- Can we develop effective screening tests for the many conditions where no reliable test is currently available?
- Is tight control of blood sugar in patients with diabetes dangerous?
- Are patients with multiple chronic conditions less likely to receive screening tests?
- Action research to speed up the implementation of effective technologies.
- Are the gaps in unmet care needs similar across countries and populations?
- Should screening strategies be the responsibility of specific medical specializations or not?
- Can we learn how to improve secondary prevention from the directly observed treatment programme strategy for tuberculosis?

## What Innovative Strategies could Fill the Gaps?

Two broad types of effort could improve the preventive care of patients with multiple chronic conditions: collaborative studies designed to answer outstanding questions (see list above) and technological interventions which aim to promote the more effective implementation of existing knowledge.

The questions that remain unanswered in relation to the prevention of multiple chronic diseases are so diverse and complex that answering them will require large, long-term research efforts that transcend traditional institutional, geographical, cultural, political and linguistic barriers.



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Richard Smith, Cristina Rabadán-Diehl, Alejandro Cravioto and Abraham Wall-Medrano wrote the initial draft of this chapter in English. Alejandro Jadad approved the draft before it was made available online, in Spanish and English, through the OPIMEC platform. This draft received important contributions in English from Simon Chapman, Katia De Pinho Campos, Murray Enkin, John Gillies, Rajeev Gupta, Yan Lijing, Beatriz Marcet Champaigne, J Jaime Miranda, Mary Ann Sevick, Ross Upshur, and, in Spanish, from Juan Antonio Guerra, Adolfo Rubinstein and Narcis Gusi. Richard Smith incorporated these contributions into a new version of the chapter, which was revised by Renée F. Lyons and approved for publication by Alejandro Jadad.

Responsibility for the content rests with the main contributors and does not necessarily represent the views of the Junta de Andalucía or any other organization participating in this publication.

### *Acknowledgments*

Carlos Álvarez-Dardet and Angela Cejudo made comments on the chapter in Spanish, and Neil Arnott, Jackie Bender, Gerald Bloomfield and Kerry Kuluski on the English version, which did not lead to changes in its contents.

### *How to reference*

Smith R\*, Rabadán-Diehl C\*, Cravioto A\*, Wall-Medrano A\*, Chapman S, De Pinho K, Enkin M, Gillies J, Guerra JA, Gupta R, Gusi N, Lijing Y, Marcet B, Miranda JJ, Rubinstein A, Sevick MA, Upshur R. [\*Main contributors] Prevention and health promotion. 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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## Management models

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### 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 21<sup>st</sup> 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).

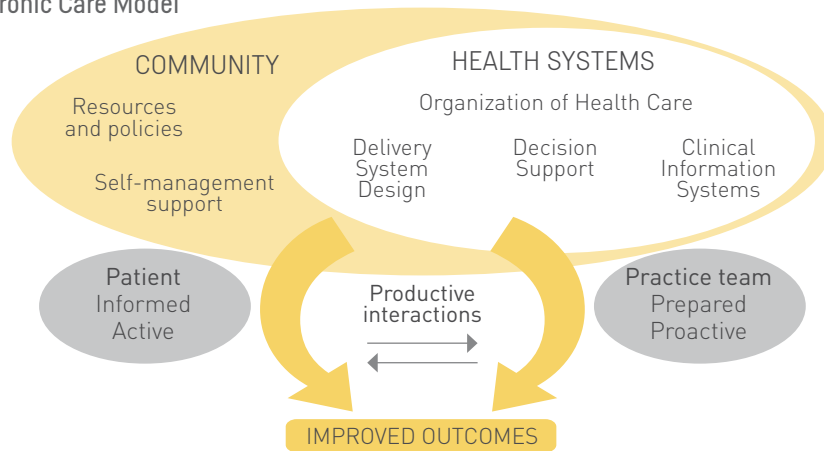
This model resulted from a number of efforts to improve the management of chronic conditions within integrated provider systems such as the Group Health Cooperative and Lovelace Health System in the USA. The development of this model was guided by systematic reviews of the literature and input from a 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

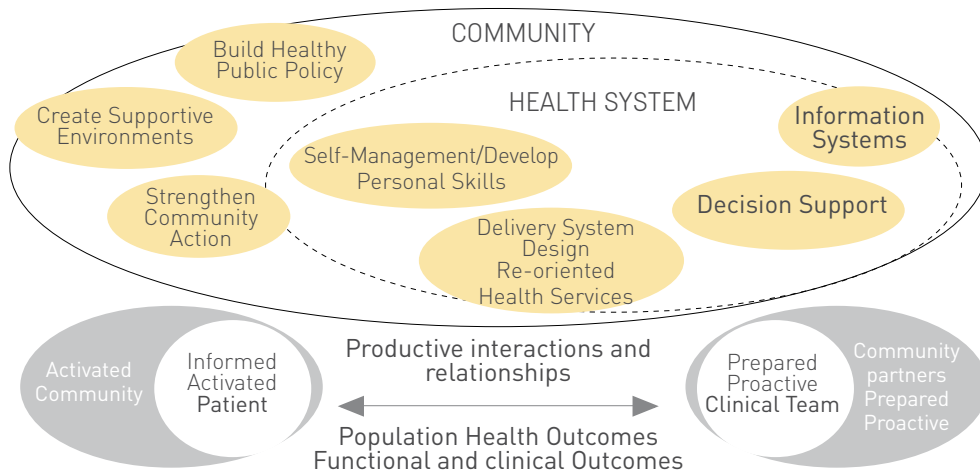
**The Chronic Care Model**



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

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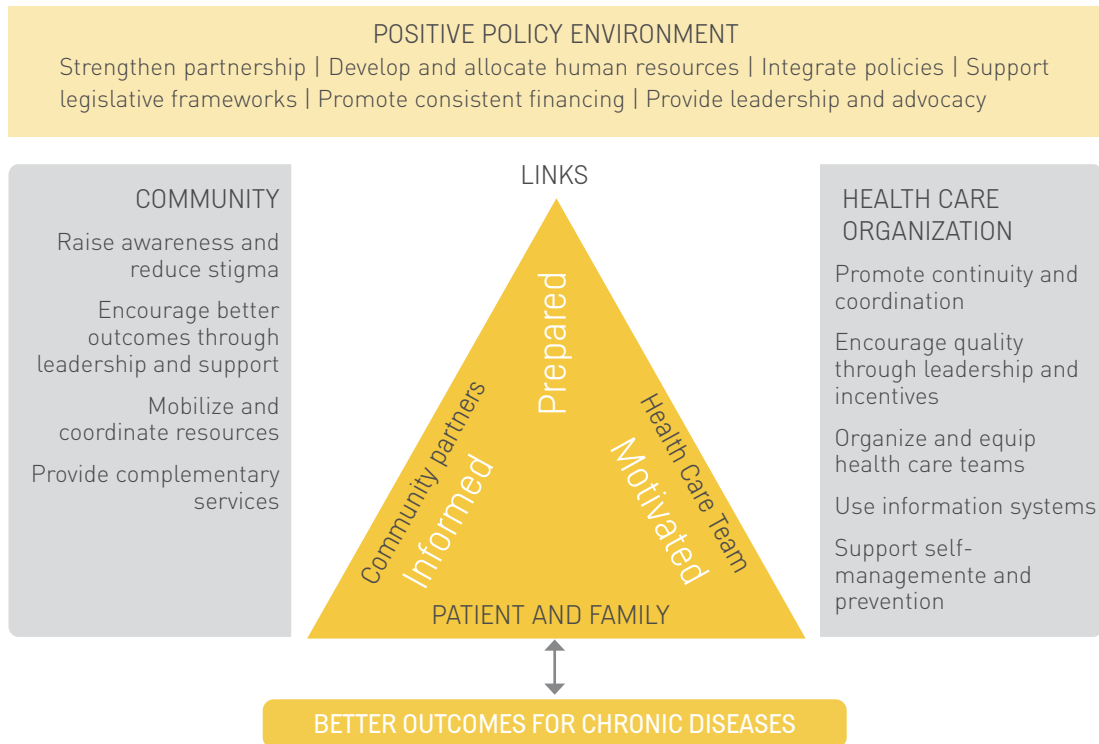
**Key elements of the ICCC model**

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.

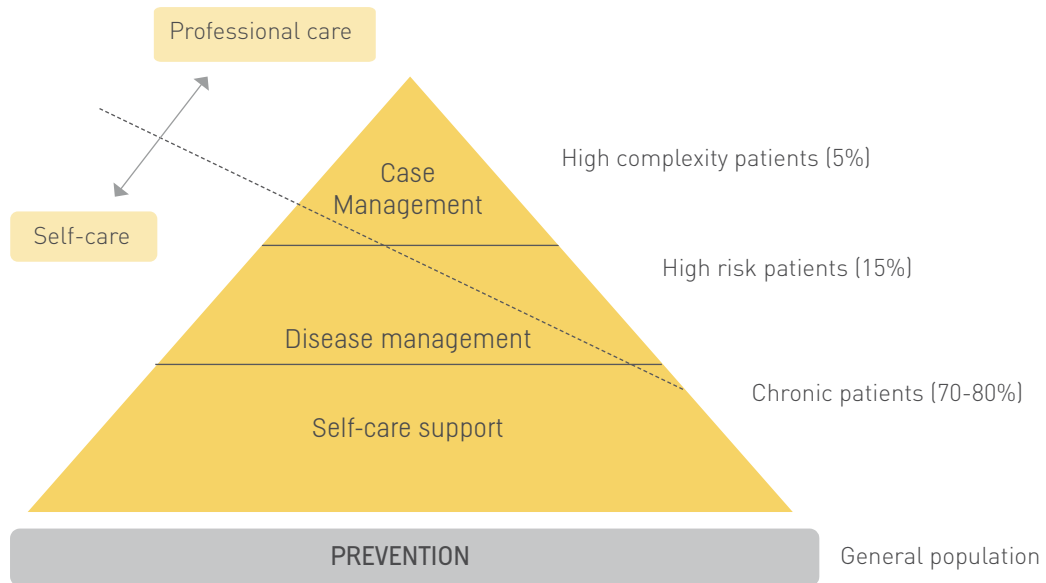
The most widely used approach to stratification is known as the Kaiser Pyramid (Figure 4), developed by Kaiser Permanente in the United States to categorize patients into three levels of intervention depending on their level of complexity. At the bottom of the pyramid, Kaiser places healthy members of 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 Permanente 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 ICCM 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

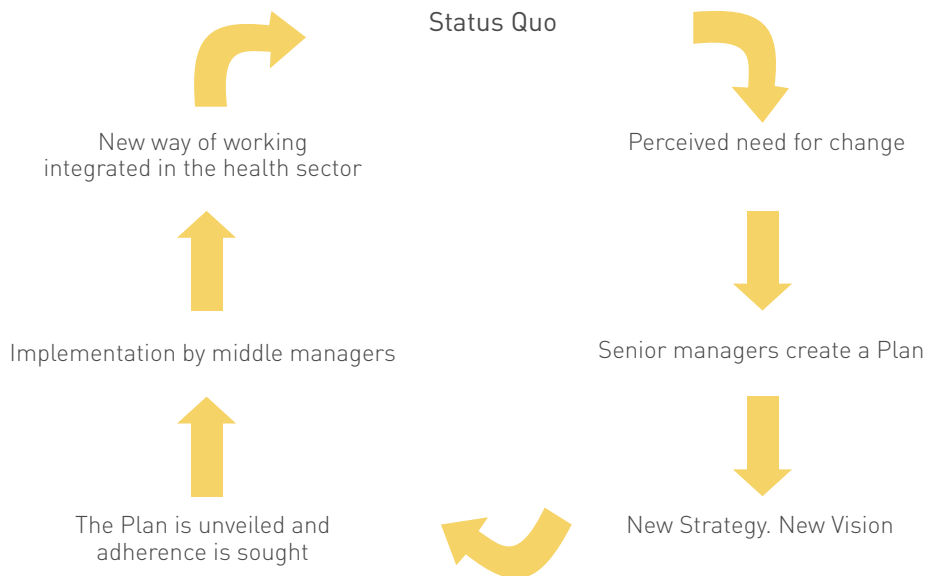


home, and better communication and cooperation between hospital and primary care following discharge. These outcomes could be achieved by means of optimal continuity of care resulting from integrated care processes that guarantee that patients remain engaged and monitored following discharge, and that 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.

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#### *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 Novak 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, Novak 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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## Patient education and self-management support

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

### Vignette: How it could be

*Ten years ago, Thomas was 52 years old, approximately 70 pounds overweight, had type 2 diabetes, hypertension, and osteoarthritis in his knees and hips. For most of his life he had been very active in competitive sports like football and basketball. Up to the age of 40 years he had normal weight for men his height and build, but gradually gained additional weight. He started to have problems with his knees and experienced several injuries requiring arthroscopic surgery. He continued to play these sports because they were important to him but in a modified manner that didn't require running and quick starts and stops. However, he paid the price for continuing and experienced increased pain and mobility problems.*

*Five years ago he participated in a community self-management program and learned helpful skills and strategies. His priority concerns were how to lose weight and to eat in a way that didn't leave him hungry all the time. He was impressed by this program and became a leader and subsequently led the program four times. He told his doctor about the self-management program and was surprised that the doctor was already familiar with the key concepts such as action planning and problem-solving. His doctor also encouraged him to join an online program where he could take the self-management program again, access his medical record, add certain types of information such as his latest HbA1c levels, communicate with peers, receive online newsletters, and find community resources.*

*Today Thomas continues to manage and cope with diabetes, but feels he has more control. He used the problem-solving process and found ways to get 30 minutes of daily exercise by parking three blocks away from the office and using the stairs instead of the elevator, and eating foods that are healthy and leave him satiated. For his home he bought a popular video fitness program and enjoys playing it with his wife and grandchildren, and he also joined an online chat room for*

*older men with diabetes. He has lost nearly 40 pounds, has much more energy and has a really great relationship with his doctor who also happy with the way Thomas is controlling his disease.*

## Summary

- Effective self-management and patient education should be regarded as essential components of a high-quality, modern health system.
- The best type of educational activities for patients experiencing chronic health conditions should include: a) disease-specific information; b) general managing skills (e.g., problem-solving, finding and using resources, working with a health care team); and c) use of behavioral strategies that increase patients' confidence (i.e., self-efficacy) in their ability to engage in behaviors needed to manage their condition on a daily basis.
- Self-management support can take place on a one-to-one basis between the patient and health care professional or in group settings led by either health providers or lay persons, or by using interactive technology like the internet.
- When patients participate in evidence-based self-management programs and interact with health professionals who use self-management support strategies, they become more knowledgeable and have higher self-efficacy. This influences their behavior as well as the behavior of their health providers; patients attain better disease control leading to improved health outcomes and higher patient satisfaction; and better healthcare utilization takes place as well as improved workplace productivity and lower costs.
- Effective self-management support programs not only involve changes at the clinician-patient level but also require change at multiple levels: office environment, health system, policy, and environmental supports.
- Use of multiple modalities has been shown to lead to improved health behavior outcomes.
- Not all patients are willing or able to engage in self-management or educational activities. In these cases, the involvement of family and significant others could be beneficial.
- Modern interactive social networking technologies have a boundless potential for enhancing self-management support.

## Why is this topic important?

Over the last decade, a dramatic rise in the prevalence of chronic conditions has emerged, altering the way in which care is delivered and received. Presently, one in every three individuals will at some time in their life be living with a chronic condition (1, 2). Coupled with aging populations and rising health care costs, these chronic conditions will create a financial burden that is expected to overwhelm the finite medical and personnel resources of any given country. The reality of this global situation will mean that clinicians will be present for only a fraction of a patient's life and these people will be living for a long period of time and mostly outside the formal health care system. Importantly, such people have an integral role in managing because the pace of disease progression and nearly all health outcomes are mediated through their own behavior (3).

One promising approach to improving outcomes and reducing health care costs associated with chronic conditions is self-management, whereby individuals, in collaboration with health care professionals, assume greater responsibility for health care decisions. In the past, almost all health care and teaching was provided by health care professionals, but there is acknowledgement that many of the clinical functions (e.g., monitoring HbA1c, blood pressure and weight) and teaching activities can be effectively carried out by patients. An inherent philosophical re-orientation is taking place whereby health professionals are seeing their relationship with patients as partners and coaches.

The growing emergence of self-management support programs not only involves changes at the clinician-patient level but also requires change at multiple levels: office environment, health system, policy and environmental supports (4). The bottom line is that self-management is good medicine, and health care without a strong self-management component does not meet quality standards.

## What do we know?

To date there is no gold standard, universally accepted definition of **self-management**. Rather, several terms are used, sometimes interchangeably, depending on the context and focus of the discussion. Although generally they are meant to describe a similar phenomenon, the terms imply varying specification regarding attributes, roles and responsibilities of both people with chronic health conditions and health care providers. Adams, Grenier, and Corrigan (5, p.57) define self-management as the *tasks that an*

*individual must undertake to live well with one or more chronic conditions. These tasks include gaining confidence to deal with medical management, social management, and emotional management.*

This definition envisions self-management as behaviors, but includes the notion of confidence and embraces clinical management as well as role and emotional management by the individual. Using this definition someone who is engaged in self-management:

- Has knowledge of his/her condition and/or its management.
- Adopts a care plan agreed and negotiated in partnership with health professionals.
- Actively shares in decision-making with health professionals.
- Monitors and manages signs and symptoms of his/her condition.
- Manages the impact of the condition on physical, emotional, occupational and social functioning.
- Adopts lifestyles that address risk factors and promotes health by focusing on prevention and early intervention.
- Has access to, and confidence in, the ability to use support services (6).

This definition of self-management provides clarity in that it focuses on the person with the chronic conditions, and further introduces the concept of self-management support, which specifies what health care providers can do to encourage self-management (5). Self-management support is defined as *the systematic provision of education and supportive interventions by health care staff to increase patients' skills and confidence in managing their health problems, including regular assessment or progress and problems, goal setting, and problem-solving support (p.57).*

By articulating self-management as behaviors and confidence to deal with medical, role, and emotional management and by using the term self-management support to describe what health care providers can do to facilitate this, Adams et al. (5) have brought greater clarity to the picture.

Another factor supporting the decision to use this definition of self-management is that it is congruent with the concept of self-management support incorporated into the Chronic Care Model (7) (Chapter 4).



The model involves two overlapping realms, the community and the health care system, with self-management support as one of the four essential components within the health care system (3). Self-Management / Develop Personal Skills refers to the support of self-management in coping with a disease, but also to the development of personal skills for health and wellness (8).

Ultimately, the model posits that when Informed, Activated Patients interact with a Prepared, Proactive, Practice Team the result is improved Functional and Clinical Outcomes. To encourage these outcomes, health authorities provide inputs to strengthen and maximize the efficiency of each component including Self-Management Support.

## Difference between patient education and self-management education

Traditionally, patient education has involved the provision of disease-specific information, teaching specific disease-related skills (e.g., how to monitor glucose levels and how to use asthma medication), and contingency planning (i.e., what to do if a situation occurs). Self-management focuses more on teaching generalized skills that patients could use to manage their condition and includes learning how to solve problems, using community resources effectively, working with one's health care team, and how to initiate new behaviors. The major differences between patient education and self-management education have been outlined by Bodenheimer, Lorig, Holman, and Grumbach (3):

- Traditional patient education provides information and teaches technical disease-related skills whereas self-management teaches skills on how to address problems.
- Problems covered in traditional patient education reflect widespread common problems related to a specific disease, whereas the problems covered in self-management education are identified by the patient.
- Traditional patient education is disease-specific and offers information and technical skills related to the disease. In contrast, self-management education provides problem-solving skills that are relevant to the consequences of chronic conditions in general.
- Traditional patient education is based on the underlying theory that disease-specific knowledge leads to behavioral change, which in turn produces better outcomes. Self-management education, meanwhile, is based on the theory that greater patient confidence in his/her capacity to make life-improving changes yields better clinical outcomes.

- The goal of traditional patient education is compliance, whereas the goal in self-management education is increased self-efficacy and improved clinical outcomes.
- In traditional patient education the health professional is the educator, but in self-management education then educators may be health professionals, peer leaders or other patients.

Both activities are, however, essential in assisting patients achieve the best quality of life and independence. While necessary, traditional disease-specific patient education is generally not sufficient for people to manage a lifetime of chronic disease care (9-12).

It is important to emphasize, however, that modern approaches to patient education, particularly outside the English-speaking world, are practically indistinguishable from self-management. This, and the risk of confusion generated by the emergence of new terms, is illustrated by the coining of such expressions as «therapeutic patient education» (TPE), which is defined by the WHO as a set of structured activities which involves «helping the patient and his family to acquire knowledge and competencies on the disease and its treatment, in order to better collaborate with the caregivers, and to improve his quality of life» (13). While increasing knowledge is one important aspect of this approach, its main aim is to increase awareness of the issues that patients face and must manage, and to motivate them to incorporate self-management and self-care behaviors in their daily lives, while addressing their own resistance to change and ambivalence and working with health professionals as partners and coaches. There is evidence that TPE can result in a number of benefits to the patient, including better quality of life, greater therapeutic compliance, a reduction in complications, decreased anxiety and a reduction in the number of acute or emergency situations (14). In any case, there is strong evidence that using behavioral strategies that teach self-directed goal-setting and action-planning, problem-solving, healthy coping, stress management, self-monitoring and skills to link to community resources improves outcomes (10, 15). There is also evidence that using more than one of these strategies increases program effectiveness (12, 15-17).

The evidence strongly makes the case that the best type of education for patients experiencing chronic health conditions should include: a) disease-specific education; b) general managing skills (e.g., problem-solving, finding and using resources, working with a health care team); c) use of strategies that increase patients' confidence (i.e., self-efficacy) in their ability to engage in behaviors needed to manage their condition on

a daily basis; and d) adequate peer role models and support networks that help in the initiation and maintenance of the desired behavioral changes.

## Delivering self-management support

Self-management support can take place on a one-to-one basis between the patient and health care professional, or in group settings led by either health providers or lay persons. These activities could take place in person or through Web-based interactive technologies.

In recent years, the main task of managing one's chronic health condition has been shifting to the patient, yet considerable responsibility still lies with health care professionals who can use their expertise to inform, activate and assist patients in the self-management of their condition.

Self-management interventions are delivered in a variety of settings; according to Barlow et al. (18) the most popular locations in which health professionals deliver programs are clinical settings (e.g., hospitals). Today a greater emphasis is being placed on health care professionals delivering self-management support and using behavioral techniques during routine clinical visits to enhance patients' abilities to be effective self-managers.

## Self-management support provided by health care professionals

### The 5As

One unifying conceptual framework used on a one-to-one basis or in groups by health care professionals is known as the 5 As construct (19). The 5 As are Assess, Advise, Agree, Assist and Arrange. Basically, this is a set of behavioral strategies to encourage patients to engage in self-management, including:

- Establishing rapport with patients to ensure that patients have opportunities to express their priority concerns.
- Setting a visit agenda with patients to ensure that both health professionals' and the patients' concerns are addressed in the visit.

- Getting patients to complete a Health Risk Appraisal at home to provide an opportunity for patients to obtain independent objective information about their health and what they need to do to address these concerns. The information can be discussed with the health professional.
- Assessing patients' readiness to enable the health professionals to use appropriate behavioral change strategies.
- Considering the Ask-Tell-Ask strategy, a technique to ensure that patients get the information they are after, or the Closing the Loop technique, to ensure patients understand the information provided by health professionals.
- Getting patients to make Action Plans is the process by which patients specify a particular behavior they will engage in.
- Teaching the Problem-Solving Process which gives patients a systematic approach to solve problems when they arise in their daily lives.
- Ensuring that follow-up takes place, facilitating the success of action plans.

These activities, which are not necessarily linear with each step following the other sequentially, have been applied to primary care interventions for a variety of behaviors (20-22).

The goal of the 5 As is to develop a personalized, collaborative action plan that includes specific behavioral goals and a specific plan for overcoming barriers and attaining those goals. The 5 As are interrelated elements and are not designed to be used in isolation, and better results will be achieved if a combination of interventions is employed, especially for complex cases (23).

Professional Associations and major hospitals have used the 5 As construct as the basis of their evidence-based best practice guidelines in providing self-management support to adults with chronic health conditions (24) and in caring for children experiencing chronic health conditions (25).

## Motivational Interviewing

Motivational interviewing (MI) is a patient-centered, directive method of communication used throughout self-management support with the goal of enhancing motivation to change behavior by exploring and resolving ambivalence (26, 27). With the widespread

dissemination of a complex innovation such as MI it is likely that reinvention may take place reflecting practitioners' particular understanding and style, and this reinvention may further add or remove critical elements. Miller and Rollnick (28) provide clarity with respect to what MI is and is not, specifically:

- MI is collaborative and person-centered.
- MI incorporates reflective listening to guide the resolution of ambivalence about change.
- MI is intended to enhance patients' motivation for change (change talk) and does not need to be based on the trans-theoretical model of change (i.e., Pre-contemplative Stage).
- MI honors the patients' autonomy and should never be used to coerce them into doing what you think they should.
- MI is a complex clinical skill that requires practice to increase proficiency, rather than a formula to be followed step by step.
- MI is a method to elicit solutions from the patient, rather than providing solutions for them in the belief that they lack something needed for success.
- MI is not necessary if the patient is ready for change.

A recent meta-analysis by Rubak (29) evaluated the effectiveness of using MI with patients who had various diseases. They found that MI produced significant effects in some areas (body mass index, total blood cholesterol, systolic blood pressure) but not in others (cigarettes smoked per day and A1C levels).

Lewin et al (30) recommended that MI be used to counsel patients/families on health behavior change. MI can be effective in brief encounters of fewer than 15 minutes, although the dose of effectiveness is individualized, assuming that increased use improves the likelihood of favorable outcomes (28). Meanwhile, some studies have shown greater efficiency when combined with other treatment methods (31). MI outperforms traditional advice-giving for a broad range of behavioral problems and diseases in approximately 80% of studies (29).

Studies show that any appropriately trained health professional (e.g., physician, nurse, psychologist or dietician) can successfully use MI skills with his or her patients (29). Miller and Rollnick (28) recognize that most health care professionals learn about motivational

interviewing through self-study or in short one- or two-hour workshops, and state that although this clinical method is simple, it is not as easy to master, requiring repeated practice with feedback and encouragement from knowledgeable guides to facilitate both skill and comfort of use.

Despite the promise that the technique holds for promoting behavioral change, there are few controlled studies evaluating its efficacy with health problems (32, 33). This point of view is consistent with that of Bodenheimer and Grumbach (34) that the effectiveness of MI in enhancing physical activity and managing chronic illness is still inconclusive.

### The Flinders Program (formerly the Flinders Model)

The Flinders Program (35) was developed at Flinders University in Adelaide, South Australia. This model enables the clinician to use measurement over time to track changes. It involves three main phases, namely:

- An assessment phase, which may involve using three tools: the Partners in Health Scale (36); the Cue and Response Interview, and the Problems and Goals Assessment Scale.
- The development of a self-management care plan where information elicited in the assessment is used to collaboratively develop an individualized self-management care plan. The plan includes the identified issues and key problem; the agreed-upon goals, interventions, a sign-off for patient and clinician and review dates.
- Monitoring and review, initiated by the clinician and using the self-management care plan as its basis. The purpose is to help the patient maintain motivation, assist the patient with problem-solving and make changes in the plan if circumstances change.

Research has investigated specific elements of the Flinders Program (36, 37), and demonstration projects have investigated effectiveness when using the complete version. These pilots, part of the Australian Statewide Chronic Disease Self-Management Initiative, investigated diabetes in rural aboriginal communities (38); mental health (39), and patients in respiratory rehabilitation (40) and found encouraging outcomes, both statistically and clinically.

## Self-management support provided by health professionals and patients

The most familiar and common way that evidence-based self-management support is delivered is through the specially designed programs that emerged during the last decade. These include both disease-specific and generalized programs led by health care professionals as well as by lay people (11, 41-43). A cursory review of recent literature reveals a growth in the development, scope, and evaluation of these programs and includes programs for: adults and children with asthma (44-46), cancer (47), COPD (48), HIV (49), bulimia nervosa (50), chronic kidney disease (51), congestive heart disease (52), dementia (53), low vision (54), macular degeneration (55), mental health (56), and stroke (57). In addition, the US National Council on Aging has also recommended several evidenced-based programs which include: Chronic Disease Self-Management Program (42), Enhanced Wellness (58), Enhanced Fitness (59), Active Choices (60), Active Living Every Day (61), Strong for Life, A Matter of Balance (62), Healthy IDEAS (63), Prevention & Management of Alcohol Problems in Older Adults: A Brief Intervention (64). These programs have been shown to be effective across a wide range of settings for people with many different types of disease and for people from different cultures and socioeconomic groups (65).

A comprehensive review of the strengths and weaknesses relating to program settings, using professional or lay leaders, using disease-specific or generic programs, and group or individual programs, has been published by McGowan and Lorig (66).

These self-management programs provide basic information, teach specific skills, and use strategies to increase patients' confidence in their ability to manage their condition (67). Specific skills include: a) Problem-solving (learning to identify a problem, generate possible solutions, implement a solution, and evaluate the results); b) Decision-making (learning how to identify warning signals when caring for their symptoms, having suitable guidelines to follow, and making appropriate choices to manage their symptoms properly); c) Resource utilization (learning how to find and use resources effectively); d) Patient - provider relationships (learning how to build relationships with health care providers); and e) Taking action (learning how to implement a specific behavior in order to achieve a goal. Patients learn to do this by making short-term, realistic and achievable action plans). Action plans are a useful resource for acquiring knowledge and for promoting health-enhancing habits, particularly when they enable patients to identify key symptoms

and interventions to relieve these, and include tips on how to solve common problems and to deal with crises.

Self-management programs usually employ several strategies to increase the patient's self-efficacy in implementing a specific behavior at a future point in time. Bandura (68) defined self-efficacy as people's judgments of their capabilities to organize and execute the courses of action required to attain designated types of performance (p.391). The key contention regarding the role of self-efficacy beliefs is that «people's level of motivation, affective states, and actions are based more on what they believe than on what is objectively true» (69). The process of developing long- and short-term goals, which is known as Guided Mastery, serves as the major means for developing and expanding behavioral competencies (68), and is an effective technique for raising individuals' self-efficacy. Other self-efficacy enhancing strategies used in the group programs include: modeling (i.e., persons with chronic health conditions leading the program); reinterpreting physiological signs and symptoms, and persuasion.

One comprehensive framework helpful in planning and evaluating the impact of self-management programs and which considers several stages of knowledge development and dissemination is the Reach, Effectiveness, Adoption, Implementation and Maintenance (RE-AIM) framework (4, 70). The five dimensions of RE-AIM build on conceptual work by Rogers (71) and Green and Kreuter (72) and focus on the following:

- Reach (proportion and representativeness of the target population willing to participate).
- Effectiveness (impact of the program in terms of outcomes and quality of life).
- Adoption (proportion and representativeness of organizations and staff agreeing to deliver the program).
- Implementation (degree to which interventions are delivered consistently as planned across staff, patients, program components, and time).
- Maintenance (extent to which behavioral change is maintained over the longer term and, at the setting level, the extent to which the program is maintained by the organization).

Traditional evaluations have mainly focused on only one or two dimensions, from knowledge development to dissemination. Examining all five dimensions yields a more



thorough evaluation, thus giving decision-makers more information on which to base their decision to adopt or discontinue a program. The Stanford Patient Education Research Center has satisfactorily addressed the RE-AIM factors in that these programs have been around since the mid 1980s and are currently being delivered in approximately 20 countries. These self-management programs have undergone randomized controlled trials (41-42, 73), dissemination studies (74), follow-up and cost analysis studies (16), and have demonstrated external validity through successful implementation, producing similar results in different countries and with different populations (75-80).

## What do we need to know?

We need a better understanding of why some patients are unable to engage in or benefit from educational and self-management efforts (81). More attention should also be paid to the role that family or caregivers should play in these cases (82).

Another major question that has not been addressed relates to the process of self-management, specifically the elements that bring about the beneficial outcomes. The recent evaluation of self-management support programs conducted by RAND (83) suggests a chain of self-management support effect, specifying that: a) as patients participate in evidence-based self-management programs and interact with health professionals who use self-management support strategies, they become more knowledgeable and have higher self-efficacy; b) this influences their behavior as well of the behavior of their health providers; c) patients attain better disease control leading to improved health outcomes and higher satisfaction levels; and d) better healthcare utilization takes place as well as improved workplace productivity and lower costs. Specific aspects within this chain of effect that need further investigation relate to why and how disease control and health outcomes are improved through self-management. It would also be worthwhile to explore the role that socioeconomic status, baseline educational level and ethno-cultural issues play in these cases.

The current understanding of how this process unfolds is that when patients acquire new knowledge and skills and gain higher self-efficacy in their ability to carry out behaviors to achieve goals, their health status and outcomes improve. The major question warranting further research is: what are the core components that are necessary to bring about this improvement? Most self-management research studies revealing positive results have utilized multiple strategies, making it difficult to delineate exactly which strategy has

been the most effective in contributing to the change in behavior or in bringing about the improvement in health status (84, 34, 85-87).

Other efforts have incorporated formal tools for the assessment of the degree of patient empowerment and «activation» for self-management. It would be important to validate those tools within the context of multiple chronic diseases (88-90).

Another area to be addressed is the development of realistic strategies and incentives for recruiting, training and retaining peer leaders for the community programs. Sponsoring organizations generally use a variety of recruitment strategies to encourage people to become peer leaders. The majority of prospective leaders then successfully complete the necessary training workshops and approximately 60% lead programs. Within this 60% of leaders approximately 10% remain involved and become program champions. While successful in some aspects, there is a need to develop strategies to retain this valuable cadre of trained and skilled volunteers.

The research design commonly used in evaluating self-management interventions has involved longitudinal randomized controlled or matched group pre- and post- program designs from base-line to four-six months. There has been little research providing information on the sustained effectiveness of these programs for longer periods of time, for example five to ten years. Having this valuable information would assist in determining the need for and types and scope of refresher and reinforcement programs.

The dissemination strategies used with self-management programs have been successful in reaching remote and rural communities and specific populations. However, these strategies may have problems with quality control and program fidelity. As with any program, trained peer leaders and health professionals may personalize and modify specific elements within the program, and observing and monitoring program delivery is difficult. Although quality control mechanisms can be implemented (e.g., program delivered by two leaders, four-day training workshops, and regular contact and support from program coordinators), there may be variation in the delivery. This is a serious concern because participants may not receive the benefits that occur when the intervention is delivered as it was planned.

From an organizational perspective there are the ongoing challenges of how to make self-management programs accessible and attractive to the target populations. Successful dissemination strategies can make the programs accessible but people may be reluctant to participate. Multiple venues (small group, telephone, mail, and

internet) do exist for these programs but information is needed to determine the best combinations and concentrations given limited resources. Scenarios that may entice members of the target population to participate could include enhancing the choice of available programs (e.g., communities having a menu of self-management programs from which to choose such as: an Online Program, Chronic Disease, Chronic Pain and Matter of Balance, etc.). Another potential strategy may be to have health professionals recommend and encourage patients to participate. Research has demonstrated that the probability of participating in a community Arthritis Self-Management Program increased 18 times when recommended by a health professional (91). The process of deciding to participate in a program is complex and an examination of marketing strategies used in the business world may shed light in this area.

Community self-management programs and the provision of self-management support strategies by health professions need to be combined into the overall health system. The term integration is commonly used to indicate how this combination should take place. However, this term is not easily defined and means different things to those who use it. To some, integration means that health professionals should coordinate the process while to others it may mean a sharing of effort and information to ensure patients receive consistent information and acknowledgement that they play an integral role in managing their health. Focused research on the best ways to integrate self-management support activities into overall care would help boost overall effectiveness and ensure that self-management is not considered a disparate and complementary service.

One concern related to the provision of self-management support by health professions deals with ensuring a sustainable remuneration and payment formula for health professionals who use practice time to provide these activities. Consistent and burgeoning research findings are indicating that disease control and health outcomes are improved with self-management support strategies, but a system that negatively impacts on one's practice and livelihood will not be welcomed or supported. Therefore the development of various administrative and organizational incentives for health professionals to engage in self-management support needs to be addressed.

## What innovative strategies could fill the gaps?

In addition to the increase of self-management support development and implementation activities, several innovative initiatives with promising potential are taking place. In the

United Kingdom, the Chronic Disease Self-Management Program (known as the Expert Patients Programme) is being delivered by the Expert Patients Programme Community Interest Company (EPP CIC), a not-for-profit social enterprise set up to meet a public need and to reinvest profits for the public good. The EPP CIC was established in 2007 to expand the work already undertaken across England in the area of self-care and self-management. The purpose is to establish the principle of individual self-management and self-care as a recognized public health measure, deliverable in a cost-effective and sustained manner, increasing the number of courses from 12,000 a year to over 100,000 by 2012. The name of the initiative derives from the belief that expert patients should be considered not only as health providers, but also as important contributors in the collective intelligence that must be developed if multiple chronic diseases are to be managed successfully (<http://www.globalalliancesms.org/about-gasms>).

Group Health Cooperative, an American consumer-governed non-profit health care system that coordinates care and coverage, is implementing new technology to facilitate remote participation in self-management.

The rapid penetration of the Internet and Web 2.0 resources, along with the convergence of mobile smart telecommunication devices and social networking tools, provides an unprecedented opportunity to foster global interventions to promote the sharing and adoption of successful experiences worldwide. The emergence «of one-to-many», «many-to-one» and «many-to-many» communication tools such as Facebook (<http://www.facebook.com>), Twitter (<http://twitter.com>) and Google Wave (<http://www.wave.google.com>) is opening up new frontiers for self-management [92].

Online social networking technology is being applied directly to promote self-management and optimal levels of patient education. Organizations such as PatientsLikeMe ([www.patientslikeme.com](http://www.patientslikeme.com)), MD Junction ([www.mdjunction.com](http://www.mdjunction.com)), WellSphere ([www.wellsphere.com](http://www.wellsphere.com)), WebMD ([www.webmd.com](http://www.webmd.com)), the Association of Cancer Online Resources, Inc. ([www.acor.org](http://www.acor.org)) [93, 94], New Health Partnerships ([www.newhealthpartnerships.org](http://www.newhealthpartnerships.org)), e-Patients ([www.e-patients.net](http://www.e-patients.net)) or the Society for Participatory Medicine, among many others, are creating unique opportunities for networked patients and their loved ones to become the main drivers of their health-related decisions (<http://participatorymedicine.org/>). Those responsible for health policy, patients' associations and caregivers have access to tools of immense power to engage in a true partnership with patients to make self-management support and education a global reality.

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### *Contributors*

Patrick McGowan wrote the draft of this chapter in English. Kate Lorig provided valuable ideas about the structure and main messages for the chapter. Alejandro Jadad approved the draft before it was made available online through the OPIMEC platform. This draft received important contributions from Esther Gil-Zorzo and Antonia Herráiz (in Spanish); Manuel Serrano (in English and Spanish); and Jackie Bender, Jennifer Jones, María Carmen Griñán Martínez and Manuel Armayones (in English). Alejandro Jadad incorporated these contributions into a revised version of the chapter, which was approved by Patrick McGowan and the other contributors.

Responsibility for the content rests with the main contributors and does not necessarily represent the views of Junta de Andalucía or any other organization participating in this effort.

### *Acknowledgments*

Juan Carlos Arbonies Ortiz made comments on the chapter (in Spanish) that did not lead to changes in its contents.

Manuel Serrano and other members of the Global Alliance for Self Management Support (GASMS) working group wrote an earlier version of this chapter, which now appears at ([link here](#)). These members are: Robert Anderson, Julie Barlow, Jane Cooper, Hermes Florez, Anne Kennedy, Doriane Miller, Jim Philips, Anne Rogers, Judith Schaeffer, Warren Todd and Andy Turner.

### *How to reference*

McGowan P\*, Lorig K\*, Jadad AR\*, Armayones M, Bender J, Gil-Zorzo E, Griñán MC, Herráiz A, Jones J, Serrano M. [\*Main contributors] Patient Education and Self-management Support. 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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## 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 polyopathologies.

## 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 poly pathology 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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### *Contributors*

Manuel Ollero, José María de la Higuera, Máximo Bernabeu and Ma Ángeles Ortiz wrote the initial draft of this chapter in Spanish. Alejandro Jadad approved the draft before it was made available online, in Spanish and English, through the OPIMEC platform. This draft received important contributions from Pritpal Tamber and Peter Bailey (in English) and from Carlos Luis Parra (in Spanish). Francisco Martos incorporated these contributions into a revised version of the chapter, which was approved by Alejandro Jadad for publication.

Responsibility for the content rests with the main contributors and does not necessarily represent the views of Junta de Andalucía or any other organization participating in this effort.

### *Acknowledgments*

Rafael Pinilla and Ana Clavería made comments (in Spanish) that did not lead to changes in its contents.

### *How to reference*

DelaHigueraJM\*,OlleroM\*,BernabeuM\*,OrtizMA\*,BaileyP,ParraCL,TamberP.[\*Main contributors] Primary care, institutional services and integrated management processes. 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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## Supportive and palliative care

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

### Vignette: How it could be

*Mr Yeo was an elderly widower who suffered from chronic obstructive pulmonary disease, ischemic heart disease, congestive heart failure and advanced prostate cancer. Despite the spread of cancer to the bones and the recurrent episodes of urinary tract infection, he suffered more from infective exacerbations of his chronic pulmonary disease and recurrent heart failure.*

*As he became frailer, his physician in the disease management program transferred his care to a colleague more skilled in dealing with poly pathology and palliative care. Having been educated about his own illness and the measures to take, Mr. Yeo knew what to do when he felt unwell one afternoon. He touched a special button on the screen of his home computer. An image of Kala, his home care nurse, appeared.*

*«Good afternoon, Kala, sorry to bother you», said Mr Yeo into the speaker, «but I'm not feeling very well. This cough which started yesterday is not settling down and I am having difficulty lying flat.»*

*As she continued to speak to him, Kala looked at the readouts from the sensors attached to Mr Yeo's telehealth unit at his bedside. She asked Mr Yeo for assistance in applying the blood pressure cuff, the pulse oxymeter, thermometer and stethoscope. She soon recognized that Mr Yeo was suffering an exacerbation of his chronic obstructive airway disease again. She quickly toggled onto the nurses-on-duty screen and noticed that advance practice nurse Sharon was on duty.*

*Sharon, can you swing by and check on Mr Yeo, he is the man living on Red Bridge Road.*

*Using her palm-top computer with wireless connection, Sharon was quickly able to access his medical records, check on the data from the telehealth unit and monitors and run an electrocardiogram. She was at his apartment within 30 minutes and quickly set about examining him. She checked his*

*medication and quickly called Dr Summers, his home palliative care physician. A course of steroids and antibiotics were ordered electronically. This was sent via courier service to his house within the hour by the neighborhood pharmacy.*

*Dr Summers took turns with Sharon to check up on Mr Yeo over the course of the next few days. In between, the easy interaction with the telehealth team by his bedside reassured Mr Yeo that there was constant attention. However, unlike previous episodes when his condition recovered well enough for him to get back on his feet, it became obvious that it was different this time around. His cough became more persistent and he was short of breath even when he was sitting up. Even as she was deciding on the care options, Dr Summers proceeded to speak to Mr Yeo to establish his understanding and elicit his views on his condition and management plans. Consistent with previously established advance care plans, a decision was made to withdraw the antibiotics and concentrate mainly on comfort measures. A family conference was also arranged between Dr Summers, Sharon, Jenny (the counselor), and Mr Yeo's daughters.*

*Yes, this is what he had anticipated, if he was facing an acute reversible condition, he would like everything possible to be done to help him recover. But if he crossed the line and had a severe exacerbation of his long-standing lung disease, he would prefer to be made comfortable and remain at home.*

*Home oxygen therapy and parenteral morphine infusion alleviated his dyspnea at home enough for him to remain comfortable. Video tele-monitoring by the program team gave his family a sense of security. He passed away peacefully about one week after the initial call, with his family by his side. Jenny called his daughter about one month after his death and she reported that Mr Yeo's family had settled back into their previous routine. His daughter was especially glad that he was able to remain at home and that he passed away quite peacefully.*

## How it is now

The following, instead, was the reality of the case.

*Mr YKC had recurrent re-admissions to hospital of increasingly longer durations and with shorter intervals between the admissions. Without a clear primary physician to call upon, this often brought him into head-on collision with an unwieldy healthcare system, which often had doctors unfamiliar with his condition, unaware of the goals of his care and unable to provide the support and care he needed. During one such admission, as he lay gasping, desperate for attention, his family was told that he had a terminal condition and to accept his impending death. The family lodged a complaint: I knew he was going to die one day, but not in such a manner.*

*The hospital-based palliative care team was called upon and adjustments were made to his medication, which included bronchodilators, the addition of diuretics for heart failure and antibiotics for chest infection, the use of steroids, and low dose opioids. Advance care planning reached a decision against resuscitation in the event of cardiopulmonary collapse and the preference for care and death at home. Despite the initial pronouncement of doom, his symptoms improved enough for him to be discharged home.*

*Before the week was up, he was back in hospital again. His complaints were similar breathlessness. The home oxygen concentrator and nebulizer had not provided sufficient relief. He had not mobilized the home hospice team that he was referred to upon discharge, as he had not found them responsive or familiar enough with his condition to call upon. In his opinion, the emergency ambulance service was by far more reliable. In any case, his family also preferred him to be admitted into the security of a hospital as he lived alone with a live-in domestic helper to assist him.*

*Proposals for admission to a hospice were not taken up by his family. They kept saying, «The hospice is not the place for my father». Finally, after six admissions in the last six months of his life, Mr YKC passed away in the familiarity of the hospital.*

*In most parts of the world, the patient would not have fared any better.*

## Why is this topic important?

Of the world's estimated 9.3 billion people, 16% will be 65 years and older in 2050. Europe will be the «grayest» region, with 29% of its population forecast to be 65 and older by 2050. Currently, Japan, Germany, Italy and Monaco have the most senior citizens aged 65 and older, with Japan leading at 20.8% (1). China, one of the most rapidly emerging economies in the world, has a current ratio of 16 elderly persons per 100 workers. This is set to quadruple to 61 by the year 2050. In Singapore, another rapidly emerging economy, the number is expected to rise three-fold from the current figure of 300,000 to 900,000 by 2030.

As described in detail in Chapter 1, the global tally of deaths is expected to rise to 74 million per year by 2030 (2). Whereas people died mainly from infectious diseases about a century ago, for many decades now chronic diseases, in particular heart disease, cancer and stroke, have predominated as causes of death (3). This is especially so in high-income countries where as many as 25% of those aged 60-65 years old and 50% of those aged 80-84 years old are affected by two or more chronic health conditions simultaneously (4). A population-based study in the Netherlands reported that of patients above the age

of 65 diagnosed with cancer between 1995 and 2002, 60% suffered from at least one other serious illness. The most frequent concomitant diseases were previous cancers, heart disease, hypertension, chronic obstructive airway disease and hypertension, with prevalence rates up to 20, 23, 26, 17 and 16% respectively (5). Consequently, more people will suffer from and eventually die with complex chronic diseases (6).

## The tragedy of unmet needs at the end of life

Since 1990, when the World Health Organization first recognized and underscored its importance as a component of cancer care, and amended its definition to include non-cancer conditions in 2002 (7), palliative care has entered into mainstream medicine in many places in the world (8). It is now widely acknowledged that palliative care involves both the patients and their loved ones, and that it should not only deal with the relief of suffering in the physical, psychosocial and spiritual domains of patients with life-threatening illnesses, but also with the need to prevent needless suffering, stressing the importance of support systems and a team approach.

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (9).

Palliative care (10):

- Provides relief from pain and other distressing symptoms.
- Affirms life and regards dying as a normal process.
- Intends neither to hasten nor postpone death.
- Integrates the psychological and spiritual aspects of patient care.
- Offers a support system to help patients live as actively as possible until death.
- Offers a support system to help the family cope during the patient's illness and in their own bereavement.
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if appropriate.
- Enhances quality of life, and may also positively influence the course of the illness.

- Is applicable early in the course of an illness, in conjunction with other therapies intended to prolong life, such as antibiotics, chemotherapy or radiation therapy, or surgery, and includes the exploration needed to better understand and manage distressing clinical complications.

Supportive care, a closely related term to palliative care, refers to the provision of the necessary services as defined by those living with or affected by chronic diseases, to meet their physical, social, emotional, informational, psychological, spiritual and practical needs during the pre-diagnostic, diagnostic, treatment and follow-up phases of care, encompassing issues of survivorship, palliation and bereavement. Supportive care refers not only to those living with the diseases, but also to carers and health professionals, and must take into account their preferences and values (11).

Despite this strong rhetoric, studies of patients with chronic diseases still show significant suffering amongst patients and needs of families and loved ones remain unmet even in countries reported to have a measure of integration of palliative and supportive care with mainstream service providers. Reviews have consistently shown high prevalence for almost all considered symptoms across all end-stage chronic disease groups (12-14). There is significant psychosocial and emotional and spiritual morbidity at the end of life (15-17). Although there is a dearth of knowledge in relation to multiple chronic diseases, the picture is likely to be grimmer, as a result of poorer coordination of resources and even fewer opportunities for patients and loved ones to ensure that the services they receive meet their needs.

There is also a small, but growing, body of literature on the burden that individuals feel they are creating for others as a consequence of their illness (18-19). The pressure for families is in fact significant. Caregivers are often middle-aged or older, and often become prone to ill health and financial difficulties as a result of looking after a loved one (20). Many are also not prepared for the care-giving process (21) and the amount of emotional energy that needs to be invested (22), and suffer from anxiety over the suffering of their loved ones and may consequently become depressed. They also face isolation and disruption of their social life and are known to suffer sleep deprivation (23).

Even though they have a similarly high symptom burden compared with patients with advanced cancer, they tend not to receive the same attention and level of symptomatic relief (24). The problem is frequently compounded by the fact that in such cases death

and dying are often regarded by health professionals as a failure; education on supportive and palliative care tends to be deficient; awareness of policymakers and managers about the need for resource allocation is usually low; and resources to enable the patients and their loved ones to adjust to the realities of incurable diseases (particularly when they are multiple) are almost always lacking.

## What do we know? So what?

### Most patients are dying in institutions

There is concern that inpatient facilities will not be able to cope with the large increase in deaths in the years to come. Despite documented preferences for home death (25-27), the majority of deaths from terminal illness still occur in hospital. This happens mostly when there is no guarantee of 24-hour support at home or back-up from specialized personnel (28).

In the United Kingdom, often considered the birthplace of modern hospice and palliative care, the percentage of home deaths fell from 31.1% in 1974 to 18.1% in 2003. If the trend continues, it is anticipated that less than one in 10 (9.6%) will die at home in 2030. Such a decline in home deaths would correspond to an increase in institutional deaths of 20.3% (29). In the United States, of the more than 1.4 million deaths in 1997 available for complete analysis, 52.8% occurred in hospital, 23.6% occurred in nursing homes and only 23.6% occurred at home (30).

Further analysis suggests that the opportunity for home death is disproportionately high among Caucasian people, and those with higher socioeconomic status (31, 32), who are married (27, 29, 33-34), who are suffering from cancer (27, 30) and living in a racially homogeneous area (35) in both the United States and other Western industrialized nations.

Observational studies have also shown that expressed preferences (36), poor functional status, intensive home care support, living with relatives and extended family support are associated with more frequent deaths at home (37).

Meanwhile, a lack of 24-hour home care services and poor coordination between health and social care services have been blamed for an increase in hospital deaths in spite of patients' preferences for death at home (38-39).



## Care at the end of life is improving slowly

Over the past 25 years, the field of palliative medicine has developed in response to the needs of dying patients and their families such that in many countries it is recognized as a specialty or a sub-specialty.

In the management of non-cancer chronic diseases near the end of life, there is clear evidence that the management of symptoms often has to go hand in hand with the continued management of the underlying illness.

Having demonstrated its effectiveness in improving assessment, documentation and care for patients in the last 24 hours to the final days, the Liverpool Care Pathway is now increasingly adopted in many parts of the world (40, 41). There is also good evidence that advance care planning led by skilled facilitators who engage key decision-makers directly over multiple sessions leads to increased utilization of advance directives (42, 43) and a better death experience at the end of life (44, 45).

It is increasingly recognized that in the management of patients with heart failure, there are reduced re-admissions and improved continuity of care with multi-component interventions (46). Although effect sizes are small, there is weak to moderate evidence suggesting that comprehensive and individually targeted interventions can relieve caregiver burden and improve satisfaction mainly in patients with dementia (47, 48). These interventions involve multi-disciplinary collaboration, address needs across care settings and over time, and facilitate communication by personal and technological means.

Despite pockets of excellence and the growing knowledge base, widespread adoption of the principles of palliative care and the dissemination of such knowledge is still lacking (49, 51). Only in recent years have major organ- or disease-specific textbooks paid much attention to supportive and palliative care of end organ failure (52, 53). Palliative care education is still not an essential component of many medical and nursing schools (54, 55). When offered, teaching tends to be fragmented, ad hoc and lacking in coordination. Most teaching is hospital-based and little attention is given to home care, hospice and nursing home care. As a result, many health professionals still find themselves standing by helplessly as patients suffer and families fret.

Besides textbook revision and improvements in health care curricula, the way forward should include the development of palliative care leaders and faculty, creating standards

of care and certification, and promoting clinical programs as venues for education and enhanced educational resources for end-of-life care (56, 57, 58).

## People die differently

Knowledge and skills alone are inadequate in the provision of good palliative and supportive care.

In their 1965 book, *Awareness of Dying*, Glaser and Strauss first described the different types of interaction that occur between the dying and those around them (59). They described the contexts of interaction based on the different degree of awareness of the dying phase: closed awareness, suspected awareness, mutual pretense awareness and open awareness. The impact of each type of awareness context upon the interplay between patients and personnel is profound, for people guide their discourse and actions according to who knows what and with what certainty.

The authors subsequently went on to describe the various patterns of dying in a book, *Time for Dying* (60), which provided the beginnings of our understanding of the different trajectories of dying. These patterns of (a) sudden and abrupt death, (b) gradual decline followed by period of more rapid decline, such as seen in cancer, (c) the entry-reentry deaths against a background of steady decline of many chronic illnesses and (d) the progressive frailty followed by death, were subsequently illustrated in a study of Medicare beneficiaries (61) and by Lunney et al (62) in their cohort study of four US regions.

One of the challenges faced by those interested in supportive and palliative care for people living with multiple chronic diseases is that the majority of hospice and palliative care programs were designed to support a cancer trajectory. In cancer, there is usually a period of overall slow decline until anti-cancer treatments are stopped, followed by a relatively rapid decline in function towards the end of life. These expected deaths are likely to have a fairly predictable terminal phase, where there is time to anticipate palliative needs and plan for end-of-life care. It may also largely match public expectation of dying. However, this does not necessarily serve the needs of those dying with other trajectories.

With the recognition of different terminal trajectories, Joanne Lynn, in a Hastings Centre Report (63), raised the notion of mass customization, in order to meet the needs of the terminally ill. Mass customization aims to define manageable populations with

similar needs to then engineer services that match the size of the population and its predictable needs.

It is estimated that about 20% of Americans will die following a course of gradual decline followed by a more rapid period of deterioration. This course, followed by most major cancers, requires excellent medical care during the long period of good function, followed by supportive and palliative care for patient and family during the period of rapid decline.

Other conditions, such as chronic heart failure and chronic obstructive lung disease, tend to follow a course of slow decline punctuated by serious exacerbations, with death occurring rather suddenly (the entry-reentry trajectory). It is estimated that about 25% of Americans follow this course. Those living with this trajectory usually benefit from (a) chronic disease management to reduce the likelihood of exacerbations and to sustain all possible function, (b) rapid intervention at the first sign of exacerbation, preferably in the home rather than the hospital and (c) good advance care planning to direct care in the event of overwhelming exacerbations.

Approximately 40% of Americans are estimated to follow the trajectory of long-term dwindling of function with death following physiological challenges such as those triggered by influenza, urinary tract infection, pneumonia or a broken hip. Half of these patients lose cognitive function. Those following this trajectory tend to benefit from supportive care over the years, requiring assistance with everyday activities and long-term interventions to promote optimal levels of comfort for patients and family caregivers.

One of the main drawbacks of this approach is its foundation on the assumption that the vast majority of patients will have the right things done for them at the right time because it is built into the system and part of the expected pattern, while downplaying the fact that good care could arise from prudent choices by individual patients, and their health professionals and caregivers.

## Dying is a multidimensional experience

Dying is not just a physical demise, and health professionals must strive to identify and meet the multidimensional needs of people with progressive disease. Centuries ago, spiritual care dominated end of life care. Although palliative care set out 40 years ago to

address the suffering of total pain, including lack of personal integrity and inner peace, spiritual distress at the end of life has remained relatively unexplored (64), although it is accepted that quality of life is modified by all dimensions of personhood (65).

Defining and assessing spiritual needs, however, is problematic. A useful definition is that proposed by the US Institute of Medicine, which states: spiritual needs are the needs and expectations that human beings have to find meaning and purpose in life; such needs may be specifically religious but even people who have no religious faith or who are not members of an organized religion have belief systems relating to meaning and purpose (66).

Spiritual issues are frequently very significant for people living and dying with lung cancer and heart failure (67). A secondary analysis of in-depth serial interviews suggests that there might be typical patterns of social, psychological and spiritual needs towards the end of life (68-70). In lung cancer, the social trajectory mirrored physical decline while the psychological and spiritual wellbeing decreased together at four key transitions: at diagnosis, after getting home after initial treatment, during disease progression, and in the terminal stage. In advanced heart failure, social and psychological decline both tended to track the physical decline while spiritual distress exhibited background fluctuations.

Knowledge about these patterns can improve the ability of health professionals to anticipate and share with patients when they are likely to be distressed. Explanations for patients and their carers about when practical, emotional and existential issues might be expected to occur, and the services available, can empower them and their carers, and this can be very reassuring for all.

This holistic view, considering each dimension of need, may lessen the multi-specialist approach, and moderate the current technological imperative with care focused on interventions to prolong life, with sometimes overzealous and futile treatment. Considering these different trajectories would bring spiritual assessment and care into focus, highlighting that many patients have spiritual issues from diagnosis of cancer or chronic life threatening illness, not just at the very end of life.

The implication of this is that spiritual support should be available for patients from diagnosis, sooner rather than later. A patient-centered approach that supports people in their own worldview while allowing for expression of fear, doubt and anxiety may help patients in their search for meaning and purpose, and prevent spiritual concerns

amounting to disabling spiritual distress. Some questions that could be asked of people living with multiple chronic diseases, and of their loved ones, in order to facilitate such an approach are [71]:

- What is the most important issue in your life right now?
- What helps you keep going?
- How do you see the future?
- What is your greatest worry or concern?
- Are there ever times when you feel down?
- If things got worse, where would you like to be cared for?

Allowing patients to raise spiritual and religious issues may be therapeutic, as may the use of a gentle prompt, such as: You seem fine today, but do you ever feel down or a bit low? This may allow them to reveal their personally felt narrative, rather than the public account they may tend to offer, as patients often have competing narratives in their minds. Patients may sometimes ask us about our own beliefs. In such cases, it might be useful to acknowledge the question, reflecting it back to the patients to ask them about their beliefs. This is because they may just be looking for an opportunity to express their own feelings and needs.

## Supportive and palliative care save money

There is evidence that enrollment into hospice and palliative care services saves money. In the US there has been an increase in Medicare dependents choosing hospice benefits, from 27% in 2000 to 40% in 2005. An independent study from Duke University in 2007 showed that hospices provide compassionate care for those reaching the end of life and save Medicare an average of \$2,300 per patient, amounting to savings of more than \$2 billion last year [72].

A 2008 paper also reported that hospice enrollment results in substantial savings in government expenditures (22 percent) among all short-stay (< or = 90 days) dying residents of nursing homes. For long-stay (> 90 days) dying residents, hospice care led to some savings (8%) among cancer residents while it was cost-neutral among dementia residents, while adding some cost (10%) for residents with a diagnosis other than cancer or dementia [73].

In hospitals, matched patients who received palliative care resulted in highly significant cost savings for the hospital compared with those who did not (74). The savings were primarily through reduced hospital stay, an increase in the death-at-home option, and a lower use of hospital emergency rooms by complex cases. In Spain, palliative care led to significant cost savings with greater efficiency and no compromise of patient care (75).

## What do we need to know?

The extent to which the illness trajectories identified in Scotland reflect what happens in other contexts and groups needs to be assessed. If they do, they could provide the foundation for the transformation of the lived experience of dying. Similar efforts are required to gain a better understanding of the social, psychological and spiritual issues faced by loved ones and caregivers in particular.

A much larger and more complex question is: What would it take to design a health system that meets the needs of patients with complex chronic diseases and their loved ones? This could be addressed at four levels, described by Donald Berwick, that characterize a high-quality health system (76): the experience of patients and their families (Level A); the functioning of small units of care delivery (microsystems, Level B); the functioning of the organizations that house or support microsystems (Level C); and the environment of policy, payment, regulation (Level D) that influences Levels B and C.

### Level A: Restorative care versus palliative treatment

One of the key challenges in the management of patients with complex chronic diseases is the need to maintain the fine balance between a disease modifying or restorative approach and the use of interventions that are mainly designed for symptom control. However, little research has been carried out on the timing of withdrawal of disease-modifying therapies in patients nearing the end of life. When would the risk-benefit ratio of aspirin given for stroke prophylaxis be considered too high for a patient who is deteriorating from cancer? Similarly, is it still reasonable to consider sympatholytic agents in a patient with cardiac failure who is also suffering from renal failure? There is even less evidence on the interaction between illnesses in a patient with multiple co-morbidities and its implication on prognoses. Research in such circumstances will be challenging but the resulting improved decision aids could certainly enable health professionals to make better judgments, and advise patients and their loved ones.

## Level B: Operationalizing knowledge

There is already a significant body of information on what constitutes good supportive and palliative care at the end of life. It is unclear, however, how these two terms complement or overlap each other, or how should they be used when communicating with patients and loved ones. The term palliative care, for instance, is fraught with negative connotations particularly for patients and family members who equate it with impending death.

Other key questions are: How can we best incorporate the knowledge available into systems of care such that health professionals have the necessary support when they need it? How do we ensure that patients and their loved ones get the care that they need?

Regarding the latter, it is important to recognize that it may be challenging for patients to express their supportive care needs to health care providers, particularly if they feel that by discussing symptoms or side effects they may: a) be viewed as bad patients or complainers, b) distract the physician from treating the underlying disease. Moreover, it is often challenging for patients to describe subjective symptoms (e.g., pain, dyspnea, fatigue) and side effects, and this task is made much more difficult for those dealing with multiple conditions. In fact, research suggests that formulating and articulating questions about symptoms such as pain is a context-dependent, time-intensive process that requires reflection, knowledge, and a good use of language (77).

## Level C: How can we build an enduring system of care?

Supportive care and palliative care service delivery is a disjointed and fragmented enterprise in most parts of the world, involving a variety of people (e.g. primary physician, nurse practitioner, disease specialist, symptom specialist, psychosocial specialist, allied health professionals, family, friends and community networks) and locations (e.g. community clinics, acute care hospitals, long-term care centers, rehabilitation programs/centers, community support organizations, hospices and the home). As a result, patients continue to be cared for in an episodic, illness-orientated, complaint- and transaction-based system. Patients who live with multiple chronic illnesses fare particularly poorly in this environment of single-organ specialty and single-setting care. Transitions across care settings are also fraught with challenging attempts to establish continuity. How do we best align our services and systems with an increasingly complex and chronically ill population?

Will the isolated family physician still have a role in the management of such patients? If so, where do they figure in the increasingly complex system of care required to manage this group of patients?

Silos of care are increasingly giving way to integrated and comprehensive systems that span care settings and disease states. We know that in many chronic illnesses, even near the end of life, it is not possible to distinguish between restorative and palliative care and such patients do not simply transit from one modality to another (78-79). How then should our healthcare system develop such that transitions between professionals with the requisite specialist skills are smooth?

### Level D: What reimbursement model will best serve the system?

Currently there are very few financial incentives for institutions and physicians to facilitate the smooth transition between care settings in most cases, let alone in those in which multiple chronic conditions co-exist. What funding mechanism will provide the most cost-effective supportive and palliative care system and yet ensure reimbursement for value-added services such as family conferences, care liaison, counseling and healthcare worker-patient communication via new media in a changing world? In Kansas they are testing a model of financial reimbursement, drawn up as an interdisciplinary service agreement between the hospital and the palliative care team, and based on achievement of quality standards with defined staffing ratios (80).

Can social systems and policies also ensure that families' needs are addressed? In Canada (81) and other enlightened countries, there is compassionate care benefit in the form of paid leave for caregivers. Can more be done to help families?

What patients need may not be what they want. Right-siting of care, a catch term in healthcare management, is often lost on patients and their families. The best and most affordable place of care for a patient may not be in the acute hospital but in an inpatient hospice facility. Patients and their families may not concur. In planning services, how do patients' preferences and knowledge about end-of-life care options interact with healthcare providers and public attitudes and knowledge about end-of-life care?

Lastly, it is important to emphasize that efforts to answer any of the above questions must take into account the special needs of children, adolescents and multi-cultural communities.



## What innovative strategies could fill the gap?

A systematic review identified the following domains and themes that conceptualize satisfaction with end-of-life care and the effectiveness of palliative care interventions (82):

- Accessibility: taking as much time as needed, non-abandonment, maintaining contact, availability, timeliness, focusing on the patient, providing needed services.
- Coordination: using other members of the team effectively and efficiently, providing coverage, maintaining consistency, helping with navigation of the healthcare system.
- Competence: knowledge and skills, symptom management, comfort with death and dying, knowing when to stop.
- Communication and relationships: personal interaction, caring, understanding, reassurance.
- Education: providing information in a way that others could understand on all relevant topics, including what to expect, financial issues, advance care planning.
- Emotional support: compassion, responsiveness to emotional needs, maintaining hope and a positive attitude, physical touch.
- Personalization: treating the whole person, not just the disease, treating the patient as unique, respecting values and lifestyles, considering the social situation, including the family.
- Support of patients' decision-making: maintaining a sense of control, avoiding inappropriate prolongation of dying.

Those who are working to improve supportive and palliative care should understand how to frame their efforts in relation to a larger context of the problem and gauge it against the domains of satisfaction with care as described above.

## The big picture-system building and customization

Innovations will have no impact if they are not incorporated into systems of care. It has been shown, for instance, that an integrated network of palliative care services including home care teams, acute hospital teams and beds in long-term care facilities can resolve many of the problems of coordination and continuity of patient care across settings (83).

Going a step further, service development should take into account the need for customization and development of systems for different groups of patients (84).

By separating patients who are near the end of life based on functional trajectories, it is possible to identify and serve population groups with sufficiently similar health care needs, rhythms of needs and priorities to make the segment useful in planning. In light of more common needs, planners are able to structure the supports, service arrays and care delivery arrangements so that they will meet the needs of anyone in that segment reasonably well, even though they may be mismatched to other segments. As is usually the case, one size does not fit all and even for patients with complex chronic diseases the trajectory may well be different and follow that of the predominant illness.

In many parts of the world this has already taken place. Palliative care services are increasingly customized to meet population needs. Though a full range of services are already present in terms of home hospice services, inpatient hospice facilities and hospital-based palliative care services, Australia (85) and the UK (86) have opted to develop end-of-life programs catering for the frail elderly in nursing homes as the conventional model of palliative care does not serve this population well. Similarly, the Program of All-inclusive Care (PACE) project (87) provides comprehensive care for the frail elderly at home in San Francisco, allowing them to spend their days, up till the last if possible, at home. This program has now been adopted in many parts of America. Other chronic disease management programs incorporating palliative care practices and expertise have shown promising results (88).

Though not labeled as such, all these microsystems have, or aspire to have, elements of the «advanced medical home» (89). The concept of a medical home was first introduced by the American Academy of Pediatrics and has been described as providing care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective (90). The key attributes of an advanced medical home include:

- A personal physician, who has an ongoing relationship with the patient and is trained to provide first-contact, continuous and comprehensive care. This physician can either be a trained family physician or a specialist.
- A multidisciplinary team, led by the physician, which collectively takes responsibility for the ongoing care of patients.
- Holistic care, which provides for all the healthcare needs of patients and their loved ones, and arranges referral to other qualified professionals if necessary.

- Coordinated and integrated care across specialty and care settings.
- Emphasis on quality and safety, which is assured by a care planning process, evidence-based medicine, clinical decision-support tools, performance measurement, active participation of patients in decision-making, information technology, quality improvement activities.
- Enhanced access availability through open scheduling, extended hours and new options for communication.
- Payment models that are appropriate for the added value provided to patients, which falls outside the face-to-face visit and supports the use of health information technology for quality improvement.

This must be supported by policies laying the groundwork for an effective healthcare system and society (91). In the many countries, policies have largely led to palliative care being embedded into the fabric of healthcare delivery (92-94). Advocacy with policy makers will thus be a key aspect in sustained gains.

## The small picture; the nuts and bolts

The use of new technology (95) has allowed for a greater attention to quality and safety through closer monitoring of patients without their needing to leave the comfort of their own homes, a very important consideration in frail individuals at the end of their lives. This can be accomplished through:

- Telehealth services-using remote telecommunications equipment for consultations and to monitor the condition of a patient, and relay information over a telephone line or wireless connection back to individual health professionals or a program's headquarters. Various sensing devices connected to a monitor by a patient's bedside can transmit pulse, blood pressure, respiratory and pulse oxymetry readings. This not only reduces travel costs and improves accessibility, but also provides a sense of reassurance to patients and their families. Use need not necessarily be restricted to the medical and nursing members of the team. The counselor or social worker can similarly make use of video conferencing devices to assess and address identified psychosocial, emotional or spiritual needs.
- Point-of-care computing with wireless or broadband grids on portable computers at the patient's home and other sites of care allows for rapid, timely and accurate

access to information and medical records (96-99), rescheduling of visits, help in retrieving essential contact information, guides the systematic assessment of patients and documents the care provided. This can also include links to evidence-based practices and decision-making tools and prompts to guidelines in patient management, preventing drug-related errors.

- Microdiagnostic technologies such as glucose monitoring and electrocardiography already exist. More can be done and made available to staff in the field as diagnostic equipment becomes cheaper, smaller and easier to use. Such technologies allow for rapid assessments, which may be especially pertinent in patients in the entry-reentry trajectory.

Technology is also revolutionizing education and the decision-making process, particularly through Web-enabled tools (100). Last Acts, a national communications campaign sponsored by the Robert Wood Johnson Foundation is a case in point. It began in 1995 and ended in 2005, and was a coalition of more than 800 national health and consumer groups that worked together to improve communication and decision-making for consumers about their own death, to change the culture of health care institutions, to change our culture and attitudes toward death. Though this highly acclaimed program has come to a close, it has left as its legacy a wealth of web content from the various projects it funded over the years. Many of these innovations (101) are still relevant to this day. In the past decade, patient and family education has gone beyond paper and person-to-person interactions. The popular media, such as movies, television, theatre, press and literature, can also be used effectively to help change perceptions of death and dying (102) and expectations of healthcare at the end of life.

The new age, however, belongs to interactive technologies and online resources (103-105). Social networks, video chat and instant messaging platforms are already shaping the way patients and their healthcare workers interact, increasing accessibility to services and nurturing a more responsive healthcare system with personalization of care. Peer-to-peer interactions through social media are in particular playing an increasingly important role, as support from people in similar circumstances is highly valued by patients (106), even for those who report high levels of support from family members (107). Such interactions can yield a unique sense of community, reassurance and practical information that cannot be gained from other supportive relationships and can improve relations with family and friends by relieving their burden of care (108).

Building these forms of communication into supportive and palliative care system development, coupled with the appropriate reimbursement incentives, will be essential in dealing with a new generation of patients in the 21<sup>st</sup> century. OPIMEC could play a key role in making this possible.



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### *Contributors*

Angel Lee and Ong Yew Jin wrote the first draft of this chapter in English. Alejandro Jadad approved it before it was translated into Spanish. The English and Spanish versions were uploaded onto the OPIMEC platform, where they received important contributions from Maria Nabal (in Spanish), Scott A. Murray (in English) and Jackie Bender (in English). Alejandro Jadad incorporated these contributions into a revised version of the chapter, which was approved by Angel Lee and Ong Yew Jin, and the other contributors.

Responsibility for the content rests with the main contributors and does not necessarily represent the views of Junta de Andalucía or any other organization participating in this effort.

### *Acknowledgments*

Carlos Álvarez-Dardet made comments on the chapter that did not lead to changes in its contents.

### *How to reference*

Lee A\*, Yew Jin O\*, Bender J, Murray SA, Nabal M. [\*Main contributors] Supportive care and palliative care. 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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## Integrative medicine

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

### Vignette: How it could be

*At age 66, Alice has had her share of health problems: she is a breast cancer survivor, has had two heart attacks, and now experiences pain in both hips and knees due to severe osteoarthritis. Once a year she journeys from her home to her local Integrative Medicine Center, where a general internist, an endocrinologist, a rheumatologist and other specialists monitor her by means of blood tests, X-rays and bone scans, and adjust her medication. Over the past year, she has been spending increasing amounts of time with the Center's alternative medicine practitioners, who have taught her about nutrition, fitness, yoga and tai chi. She feels this comprehensive approach has helped her to live a more satisfactory and meaningful life.*

### Summary

- Integrative Medicine is a model of health care based on a systematic approach, which is designed to bring together the best available knowledge from both conventional and traditional alternative medicine (TCAM) in order to address the biological, psychological, social and spiritual aspects of health and illness. It focuses on respect for the human capacity for healing, promotes collaboration amongst practitioners, and stresses the importance of the relationship between the practitioner and the patient and of evidence based health care.
- TCAM incorporates several different approaches and methodologies, including mind-body medicine (e.g. meditation), manipulative and body based therapies (e.g. chiropractic); energy medicine (e.g. Reiki), holistic medical systems (e.g. TCM,

Ayurveda); and biologically based therapies (e.g. dietary supplements, herbs and vitamins).

- TCAM in the Western world is a consumer-driven movement in which patients tend to self-educate, self-diagnose and self-treat themselves using interventions that may help or may also exacerbate illness.
- The World Health Organization is supporting health care policies designed to institute TCAM along with conventional medicine around the globe. However, the broad range of healing philosophies, approaches and therapies embraced by TCAM continue to generate resistance within mainstream Western medicine. As a result, TCAM, and, by default Integrative Medicine, is not used, accepted, studied, understood or made available within most conventional health care institutions around the world.
- As populations throughout the world continue to age, the concomitant increase in the prevalence of complex chronic diseases will make Integrative Medicine an inevitable component of a modern health system.

## Why is this topic important?

The world is rapidly changing and vast amounts of information are readily and quickly available, literally at our fingertips. Yet health and disease are concepts that have evolved slowly, cautiously and incompletely. For more than 200 years, biomedicine has approached diseases by studying the processes which underlie them (pathogenesis), inferring causal connections and developing specific approaches to modify these processes by means of therapies. This pathogenic approach, which is highly successful in acute and traumatic conditions, is often ineffective in chronic disease, primarily because of the complex, multi-factorial nature of most disorders, which does not permit simple causal, linear inference or standardized therapeutic interventions that view individuals as cases of malfunctioning organs or systems and undervalue the socio-cultural and humanistic aspects of care (1). Unfortunately, the surge in technological development, the increased need for immediate reward and the overestimation of our capacity to deal with human suffering have driven the medical system even further toward this disease based approach to health care. The results are a diminishing public faith in the medical establishment and the rise of alternative medical philosophies and practices. The real crisis in medicine and healthcare in general today may not really be about economics,



but about the loss of the fundamental human relationship between the health system and the public; between health professionals and patients (2). Ancient models of care are now re-emerging, allowing physicians and other health professionals to refocus on the unique experience of illness for the individual and the community (3, 4).

Within this context an approach known as Integrative Medicine is evolving. It focuses on health and healing through the integration of conventional and traditional complementary and alternative medicine (TCAM). Integrative Medicine emphasizes the relationship between the patient and the health practitioner, and the responsibility of the latter to enable the patient to benefit from a full array of modalities that can be shown to benefit our health. It addresses the biological, psychological, social and spiritual aspects of health and illness and has a strong focus on preventive health (5-8).

At the micro (clinical) and meso (health services) level, IM seeks to harmonize the treatment methods which characterize conventional biopharmaceutical medical approaches with the TCAM approaches various cultures have adopted for the restoration and maintenance of health (9, 10).

At the macro level, Integrative Medicine promotes health care systems that integrate self-care, lifestyle based interventions and TCAM with conventional medicine through rational, comprehensive patient evaluation and monitoring. It emphasizes respect for the human capacity for healing and our awareness of our own health. Promoting collaboration among practitioners, it also stresses the importance of the relationship between practitioner and patient, supporting individual behavioral changes focused on evidence based health care, be it conventional, alternative, or complementary (11, 12).

Given the undisputedly important role that TCAM plays in most cultures around the globe, the World Health Organization (WHO) has recognized it as a source of culturally acceptable, affordable and sustainable primary health care services (5). Such services, according to the WHO, include any health practices, approaches, knowledge or belief incorporating plant, animal and mineral based medicines, spiritual therapies, manual techniques and exercises, applied singularly or in combination to treat, diagnose and prevent illnesses or maintain well-being (6, 7). Such therapies may be used alone, as an alternative to conventional therapies, or in addition to conventional, mainstream medicine to treat illnesses and promote wellbeing (5, 13, 14). Another important aspect of TCAM is that it views the patient holistically, seeking to shift from a disease treatment approach to addressing patients as individuals with the capacity to contribute to their

own well-being and choices (15, 16). This emphasis on making sure the patient's environment, choices, emotions and spirit are considered becomes ever more relevant for people living with multiple chronic diseases, whose ill health is caused and fuelled by the complex interaction of multiple factors (17-19). Such complexity is also taken into account in relation to efforts to evaluate interventions, as advocates of integrative medicine call for whole systems research, departing from the linear and reductionist approaches that pervade the assessment of conventional health interventions (20, 21).

Not surprisingly, the broad range of healing philosophies, approaches and therapies embraced by TCAM generate resistance within mainstream Western medicine. As a result, TCAM, and, by default Integrative Medicine, is not used, accepted, studied, understood or made available within most conventional healthcare institutions around the world.

## What do we know?

Despite the resistance from conventional mainstream health institutions, Integrative Medicine services for chronic disease prevention and management seem to be growing at a fast pace, largely mediated, demanded, pursued and sustained by the public (19, 22, 23). A number of surveys indicate that TCAM use has increased around the world, regardless of socioeconomic status or cultures. However, in developed countries most users tend to be younger, affluent and well educated people hoping to gain control over their disease and its management (24-31).

Through its Traditional Medicine Program, the WHO estimated that 80% of the world's population currently uses TCAM as a primary source of medical treatment (32, 33). Most people living in Africa, Asia and Latin America use TCAM to help meet some of their primary healthcare needs. In Africa, up to 80% of the population uses TCAM for primary health care, while in India the corresponding figure is 70% (34). The percentage of the population that has used TCAM at least once in the past 10 years in high-income countries is also significant, the figures being 42% in the US, 48% in Australia, 49% in France and 70% in Canada (24, 35).

A 2002 survey from Harvard University indicated that approximately 72 million US adults used TCAM mainly to control diseases, such as diabetes, cancer, depression, chronic liver disease and arthritis, and for pain management. TCAM which is used solely for pain

relief includes acupuncture, low-level laser therapy, meditation, aromatherapy, dance therapy, music therapy, massage, herbalism, therapeutic touch, yoga, osteopathy, chiropractic, naturopathy and homeopathy (25). This study also revealed that the prevalence of TCAM use appears to have been fairly stable over the years, hovering at around one in three adults in the country as a whole. These findings were confirmed by the 2007 National Health Interview Survey (NHIS) in the United States, an annual in-person survey of Americans health- and illness-related experiences, which indicated that approximately 38% of adults (about 4 in 10) and also approximately 12% of children (about 1 in 9) are using some form of TCAM. Non-vitamin, non-mineral natural products are the most commonly used therapies among adults and are likely to be used for musculoskeletal problems, such as back, neck or joint pain (30).

In patients suffering from severe depression, TCAM use may be higher than 40% and 50% of cancer patients use these methods in conjunction with conventional cancer treatments (36). A literature review of 26 surveys from 13 countries, including the USA, Germany, the UK, Norway, Austria, Australia, Taiwan, Italy, Argentina, Finland, Holland, Switzerland and China, suggested that the use of TCAM amongst cancer patients is common, with an average prevalence rate across studies of 31% (range 7% to 64%) (37). More recent studies suggest that the use of TCAM could be considerably higher, with some studies reporting rates of 83% in an outpatient sample of 453 patients (38), 70% in a sample of 356 colon, breast and prostate cancer patients (39) and up to 73% in 14 European countries (40).

In paediatric patients the rates seem equally high, ranging from 33% in the UK (41) to 84% in the USA (42).

For cancer herbal medicines and remedies, used together with homeopathy, vitamins/minerals, medicinal teas, spiritual healing and relaxation techniques, appear to be the most commonly used TCAM therapies (40, 43). Apart from cancer management, TCAM use is most often associated with the «chronic disease triad» - arthritis, musculoskeletal disorders and stroke; with people who experience low satisfaction with care; and with those who have strong cultural beliefs (44).

The use of TCAM also appears most likely among people who have been diagnosed with chronic disease (23) and among health conscious people who are interested in interventions that could help them prevent diseases (45).

An emphasis on integration does not imply shunning conventional medicine, nor is there the assumption that all modes of TCAM are worthwhile (46). Advocates of TCAM hold that their interventions and methods are effective in treating a wide range of major and minor medical conditions, and that integrative medicine interventions encourage positive behavioral changes in terms of diet, exercise, stress management and emotional well-being (6, 7, 47). However, most treatments are recommended on the basis of opinion rather than research. Obviously, opinion and evidence can differ without either of them necessarily being wrong and an intervention could be recommended without the back-up of research simply because trials are not yet available. As pointed out by Ernst and his colleagues, the absence of evidence of effectiveness does not imply the absence of effectiveness (13).

There is limited evidence, however, about the effectiveness, potential harm and overall cost of integrating TACM with conventional Western care approaches (22, 48) and there is concern about Integrative Medicine, particularly when clear definitions and descriptions for many interventions and terms are lacking (49, 50). There is also a real need for standardized Integrative Medicine education (8, 51, 52, 53) and more thorough scientific research into the use and efficacy of TCAM in chronic disease, as well as the appropriateness, quality, availability and cost of TCAM modalities in the current healthcare system.

A number of studies and systematic reviews which address the evidence for the efficacy of TCAM in chronic conditions have been published and recent trials have reported both positive (54, 55, 56, 57) and negative (58, 59, 60) results for specific interventions. However, the evidence varies widely in different countries and types of study.

In 2009, an attempt to distil the evidence available from clinical trials and systematic reviews concluded that only 7.4% of 685 treatment/condition pairings were based on what the authors considered to be sound evidence (a composite of the weight and direction of the studies). From this analysis, 51 were characterized as «having maximum <weight> in terms of evidence as well as being clearly positive» (61). The table below provides a list of the most widely used TCAM treatment/condition pairings for which there seems to be sound evidence. Although valuable, this approach must be complemented with a much deeper analysis of the data that are available before conclusions are drawn in relation to the management of people living with multiple chronic diseases.

Table 1

## CAM Treatments Based on Sound Evidence\*

INTERVENTION	DISORDERS
Acupuncture	Nausea/vomiting induced by chemotherapy
Acupuncture	Osteoarthritis
African plum	Benign prostatic hyperplasia
Allium vegetables	Cancer prevention
Aromatherapy/massage	Cancer palliation
Biofeedback	Hypertension
Biofeedback	Migraine
Chondroitin	Osteoarthritis
Co-enzyme Q10	Hypertension
Diet	Rheumatoid arthritis
Ephedra sinica	Obesity
Exercise	Cancer prevention
Exercise	Cancer palliation
Exercise	Chronic fatigue syndrome
Exercise	Depression
Exercise	HIV/AIDS
Fiber	Irritable bowel syndrome
Ginkgo biloba	Alzheimer's disease
Ginkgo biloba	Peripheral vascular disease
Glucosamine	Osteoarthritis
Green tea	Cancer prevention
Group behaviour therapy	Smoking cessation
Guar gum	Diabetes
Guar gum	Hypercholesterolemia
Hawthorn	Chronic heart failure
Horse chestnut	Chronic venous insufficiency

<b>INTERVENTION</b> (continued)	<b>DISORDERS</b> (continued)
Hypnotherapy	Labor pain
Kava	Anxiety
Massage	Anxiety
Melatonin	Insomnia
Music therapy	Anxiety
Oat	Hypercholesterolemia
Padma 28	Peripheral vascular disease
Peppermint/caraway	Non-ulcer dyspepsia
Phytodolor	Osteoarthritis
Phytodolor	Rheumatoid arthritis
Psyllium	Constipation
Psyllium	Diabetes
Red clover	Menopause
Relaxation	Anxiety
Relaxation	Insomnia
Relaxation	Nausea/vomiting induced by chemotherapy
S-adenosylmethionine	Osteoarthritis
Saw palmetto	Benign prostatic hyperplasia
Soy	Hypercholesterolemia
St John's wort	Depression
Stress management	HIV/AIDS
Tomato (lycopene)	Cancer prevention
Vitamin C	Upper respiratory tract infection (treatment)
Water immersion	Labor pain
Yohimbine	Erectile dysfunction

\*From Ernst 2009 How Much of CAM is Based on Research Evidence?

Probably the most widely evaluated approach has been the combination of medicinal plants with conventional drugs. The WHO estimates that of the 35,000 to 70,000 species of plants that are used for medicinal purposes around the world, 5,000 have been submitted to formal biomedical scrutiny (33). Of these, a much smaller number has been evaluated to confirm either beneficial or adverse effects, particularly those associated with herb-drug interactions (62-64). Nevertheless, in many countries scientific evidence of efficacy is beginning to emerge from randomized controlled trials in which herbs compare favourably with placebo. In addition, a number of studies indicate that herbal products may in fact complement and improve the efficacy and/or adversely affect the properties of commonly used drugs (65).

Much work has been done in recent years to increase the credibility and acceptance of herbal medicines and to comply with new regulations that address quality issues, good manufacturing practices and science-based research. Government and non-government institutions around the world are spending considerable resources to facilitate research in this area and to increase the body of evidence about the value of herbal medicines in improving human health (66-70).

An important outcome and ultimate goal of Integrative Medicine is to reduce the cost of medical health care without sacrificing quality of life. Two key principles: Normalization and Substitution have been identified as critical for this to occur. Normalization enables self-determination. The principle of substitution involves replacing more costly services for cheaper services. Within the mainstream health system, this happens when a health insurance company or a healthcare facility uses generic instead of brand name drugs or when patients are discharged so that they can go home following a surgical procedure, armed with the resources they will need to engage in self-care. Ultimately, cost is reduced while patient empowerment is increased, but without jeopardizing the overall health outcome, thereby reducing the burden on healthcare workers (71, 72).

In some settings, however, substitution and self-care do not happen by choice. In the poorest communities in the world, people are forced to rely on traditional systems and traditional healers, as well as on herbal medicines and concoctions of questionable quality as substitutes for conventional care, in an effort to compensate for limited access to appropriate resources. But this limited access is not only due to a lack of money but also to the lack of access to appropriate medicines. In fact, the WHO reports that less than 1% of the nearly 1,400 pharmaceutical drugs registered between 1975 and 1999 were for diseases affecting the poorest people in the world (73, 74).

Although the WHO has instituted plans and centers to help countries integrate traditional medicine with national health care plans [75], the wealthiest nations in the world continue to use TCAM as a complement rather than as an alternative to mainstream care. In the past decade, integrative medicine centers have opened all over the world. In the US, the American Hospital Association's 2003 Annual Hospital Survey showed that the percentage of hospitals that offer TCAM has more than doubled in less than a decade, increasing from close to 9% in 1998 to almost 20% in 2003. Out of 1,007 respondents, 269 hospitals stated that they offered some CAM services. Their top three reasons for doing so were: patient demand (83%); organizational mission (69%); and clinical effectiveness (61%). 24% of the hospitals which are not currently offering TCAM stated that they planned to do so in the future.

Patients usually pay out of their own pocket, although some services such as nutritional counselling, chiropractic treatments and biofeedback are more likely to be reimbursed by insurance companies [76]. A similar survey in 2007 indicated that more than 37% of US hospitals, up from 26% in 2005, offer one or more TCAM therapies with 67% of survey respondents stating that clinical effectiveness was the top reason for choosing them [77].

## What do we need to know?

- How should TCAM interventions and Integrative Medicine be evaluated?

One of the biggest challenges in relation to TCAM is the lack of accepted research methodologies to evaluate complex interventions that aim to treat chronic diseases, particularly when two or more are present in the same person, or at least to prevent their progression. As noted in the previous section, little is known about the efficacy and adverse effect profile of many specific TCAM interventions and practices. Similarly, there are few guidelines on how to assess the impact of any TCAM interventions on healthy people.

- What are the socioeconomic implications of Integrative Medicine?

Many socioeconomic challenges also remain unaddressed. Highly developed mass marketing campaigns invite and entice consumers to return to basics, appealing to the general public to go back to nature, without taking into consideration the myriad of differences between the old natural, agricultural peasant society and the technology-



driven, industrialized distribution chains of today. It is unclear whether existing government agencies, professional associations and consumer advocacy groups might play a significant role in protecting the public from unscrupulous TCAM marketeers, at the same time promoting access to beneficial products.

Another set of challenges is societal in nature. We have become a society in which we believe that we are entitled to cures for all our diseases, regardless of how we neglect and misuse our bodies. We are willing to pay for pills and therapies to cure self-inflicted conditions that result, to a large extent, from our own sedentary and stressful lifestyles and gluttony. We want quick fixes to our problems, no matter how little we understand them, but we are unwilling to take any risks or to participate in research that may improve our understanding about their benefits or risks. We want protection from unscrupulous quacks, but then we declare a conspiracy against and show a lack of trust in the very institutions we created for our protection.

- Could Integrative Medicine promote the demedicalization of multiple chronic disease management?

We can define medicalization as a process whereby nonmedical problems become defined and treated as medical problems. It could be argued that childbirth, menopause and obesity are examples of this. Far less commonly, demedicalization can be defined as the process whereby a condition or life process under medical jurisdiction is reconsidered so that it is no longer regarded as a medical problem and therefore no longer requires the intervention of medical personnel. Historically, homosexuality could be seen in this context. How about ageing? Even without co-existent chronic disease, the ageing process brings physical co-morbidities, emotional traumas, such as bereavement, and social concerns, such as loneliness. Have these issues been medicalized? Are financial interests leading us to do more harm than good, for example by converting the symptoms associated with normal ageing processes into new diseases that require treatment? If so.

- Could Integrative Medicine promote greater acceptance, among patients and caregivers, of the unavoidable suffering associated with multiple chronic diseases and the ageing process?

The literature suggests that there are two types of individual approaches to chronic diseases: an accepting and progressive approach or a non-accepting and regressive approach. A study evaluating the life of coronary artery disease patients from their own

perspective revealed that participants who demonstrated an accepting and progressive attitude to life achieved a better level of rehabilitation than those with a non-accepting and regressive attitude [78].

The Judeo-Christian approach to suffering implies acceptance, as well as coping, within the broader concept of a perfect/higher purpose. Suffering is transient and it has an eternal perspective.

Accepting chronic diseases as a part of life can impact not only on their management, but also on the extent to which they are perceived as a burden. A person's attitude, as well as his or her spirituality, values and thoughts, influence his experiences of both health and illness. This depends on factors such as: irreversibility of the condition, availability of medical technology to improve it, the desire of the individual to live a full life and a realistic approach to life and death. When confronted with traumatic or chronic conditions, patients may feel the need to understand their own experiences in the context of their spiritual views. The incorporation of culturally appropriate spiritual practices, alongside the administration of medical care, in an integrated and holistic manner may be needed for a meaningful demedicalization of care.

- How could Integrative Medicine support health promotion efforts at the community level?

Healthy environments, in particular healthy cities, where most of the world population live, are currently the focus of WHO programs which aim to recognize that people form an integral part of the earth's ecosystem and that their health is therefore irrefutably interlinked with the environment.

A healthy environment may not only help to prevent chronic complex disease. It may prove essential in coping with non-drug therapeutic strategies for these pathologies. Most people with multiple chronic diseases are elderly. Cities could adapt their structures and services to make themselves more accessible and inclusive for older people and individuals with disabilities. Community action involving other sectors besides the health sector is required. Town planning could include more outdoor spaces, adequate transportation and housing, encouraging social participation and providing health care facilities with easy access [79].

## What innovative strategies could fill the gaps?

A future in which we understand the intrinsic value of integrative approaches, focusing on the whole person and prescribing effective combinations of TCAM and conventional interventions to treat and prevent illness, alleviate pain and improve quality of life for people with complex chronic diseases, will require unprecedented levels of collaboration between regulators, industry, health care practitioners, researchers and patients/consumers.

There are some encouraging examples of this type of collaboration (80). For example, the WHO has issued Guidelines for the Assessment of Herbal Medicines. Based on the classical paradigm, they follow the traditional approach to validating quality, safety and efficacy which is used for conventional pharmaceutical products, but with one major difference. The starting point is to look at the effects of interventions in human instead of animal models. By taking into account traditional experience with herbal medicine and viewing commercially based datasets, the apparently uneventful use of a substance for long periods is taken as evidence of its safety. Manufacturers are then encouraged to support research which seeks to develop a drug or a derivative, following good development practices and standard operating procedures based on the initial identification, collection and processing of plant or natural product materials. However, major challenges remain, particularly in relation to the marked variations in source material, the lack of understanding of the synergistic effects of multiple chemical ingredients and the absence of information on the potency of various formulations.

Given its reach and global role as an overseer and de facto coordinating body for issues related to human health, the WHO may need to be more aggressive in promoting better chronic disease management. Indeed, it has already encouraged the publication of reports proposing several detailed options to facilitate the implementation of Integrative Medicine services as part of programmed national health care system reforms (22). This work, which already involves substantial international collaboration, includes valuable information for those who are interested in harmonizing science and traditional medicines in diagnostics and health education, and who employ complementary treatment methods, so that they can ensure the optimal quality of CAM products in their own countries. Joint efforts with other global bodies, such as the World Trade Organization, will be needed to achieve these goals, with industry and health professional organizations playing a more prominent role.

The documentation of the safety and efficacy of TCAM practices and interventions, as well as innovative methods to develop cheaper, faster and effective medicines, should be encouraged (74). Nowadays, this is being facilitated by powerful information and communication technologies that permit the easy tracking of individuals and societies, tendencies and styles in real time. These technologies could also strengthen our efforts to gain a much better understanding of the basic sciences, chemistry, physics and mathematics, underlying the effects of TCAM, enabling us to shed light onto sorcerers' wisdom and mystical forces and to improve our comprehension of the incredible complexity of the processes involved in healing.

Other initiatives, such as Integrative Health Coaching at the Duke Integrative Medicine Center, are currently being implemented at Integrative Medicine Centers (81). This personalized health planning and coaching program expands conventional behavioral change models by linking behaviours to personal values in the context of life as a whole and focuses on the relationship and partnership dynamics between patients and a team of providers (82). This team includes physicians, TCAM providers and health coaches, amongst others.

The importance of Integrative Medicine as a means of addressing the mental, emotional and physical aspects of the healing process and the need for greater patient involvement in health care was considered in a report by the Institute of Medicine in the US as a spin off from a Congress on Integrative Medicine in Public Health held in February 2009. The congress included reviews of the state of the science, assessed its potential and priorities and began to identify the elements of an agenda to improve our understanding, training, practice and other actions that might help improve prospects for the contributions of integrative medicine to better health and health care (83). More gatherings like this should not only be encouraged but should also be linked to large-scale projects designed to fill existing gaps.

The gap between knowledge and practice, conventional and traditional, and alternative and integrative is still wide, despite the fact that health professional associations are starting to concede value to TCAM interventions, health care professionals are enrolling in TCAM-related continuing medical education courses and consumers are seeking information about interventions they believe to be good for them, while at the same time advocating for more freedom, fewer regulations and better access. Studies on the delivery, organization and financing of different integrative healthcare models and medical and public education, which is geared to expanding the reductionist disease-

oriented model and understanding the changing dynamics of TCAM, should be regarded as a priority by funders of research and health services.

As populations throughout the world continue to age, the concomitant increase in the prevalence of poly-pathology will make TCAM an inevitable component of a modern health system. Now it is our turn to ensure that TCAM is properly integrated with conventional biomedical options, as part of a relationship with the public that is built on trust, respect and commitment to achieving optimal levels of well-being. A healing environment should be the ultimate goal for all.

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#### *Contributors*

Carmen Tamayo, Alirio Arreaza and Christina Almonte wrote the initial draft of this chapter in English. It received important contributions from Mario Barbagallo, Ligia Dominguez, Josephine Fagan, Renée F. Lyons and Kerry Kuluski (in English), and Jaime Espín (in Spanish). Alejandro Jadad incorporated these contributions into a revised version of the chapter and approved it for publication.

Responsibility for the content rests with the main contributors and does not necessarily represent the views of the Junta de Andalucía or any other organization participating in this publication.

#### *How to reference*

Tamayo C\*, Arreaza A\*, Almonte C\*, Barbagallo M, Dominguez L, Espín J, Fagan J, Lyons RF, Kuluski K. [\*Main contributors] Integrative Medicine. 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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## Socioeconomic implications

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

### Vignette: How it could be

*Laura felt very pleased during the ceremony in which she handed the reins of the Ministry of Health and Wellbeing to her successor. She could not believe that so much had changed in just under a decade in the job. As a seasoned politician, economist and general practitioner, she was particularly proud to report how the joint effort of tens of thousands of committed people from all over the country and the world, had resulted in the elimination of most of the problems associated with the management of polypathologies, which had remained intractable for generations. She could remember with great satisfaction the day when the daring and detailed plan that she and her team had prepared was met with unconditional support from the head of state, legislators, the media, corporations, academic organizations and community agencies. With their support, it was dream-like to witness how bold policies and swift reallocation of internal resources had led to the implementation of a comprehensive and generous system of incentives that aligned the interests of all groups of stakeholders with the health needs of people living with multiple chronic diseases. Exceeding all of her own expectations, she had seen how this collective effort resulted in a significant improvement in all health indicators at a progressively lower cost! It was particularly joyful to remember the extraordinary support given by other members of cabinet to tackling disparities in health determinants; the enthusiasm with which the public had promoted the implementation of evidence-based secondary, tertiary and quaternary preventive interventions; how all the media and academic institutions had made patient education and self-management programs available to all those who needed them; how frontline clinicians, managers and caregivers had proposed, developed and introduced new health services; how clinicians with such a diverse background had embraced Integrative Medicine at all levels; and how many young people had pursued new health professions*

*that now made supportive and palliative care services available to anyone, anywhere. With over 99% of health care services provided to those with multiple chronic diseases in the community, her country had become a beacon for others to follow.*

*Laura was now ready to embark on the next phase of her career. She had accepted an offer from the World Health Organization to head a global task force supported by her existing network of collaborators, and leading political, academic, clinical, community and corporate organizations, to promote the transformation of the management of multiple chronic diseases in all inhabited continents of the globe.*

## Summary

- Care for people with chronic diseases currently consumes the largest share of the healthcare budget in most countries, regardless of their level of income, and its overall share is expected to rise significantly in the decades to come. Care for people with multiple chronic diseases accounts for the greatest consumption of resources.
- There is a dearth of data on the economic, social and political impacts of multiple chronic diseases.
- Close integration and coordination of social and health services appear to be essential for the successful management of multiple chronic diseases. However, most policy, economic and management models seem to be anchored in the past by excessive compartmentalization and a lack of dialogue across levels of care, sectors and geographic regions.
- Given the potential political, societal, and economic challenge presented by inappropriate handling of multiple chronic diseases and the failure of market forces to contain them, political intervention, ideally backed by a global network of influential political, academic, clinical, corporate and community organizations, is justified.

## Why is this topic important?

It is now obvious that the demand for health services is outstripping available resources in every society in the world, threatening not only the sustainability of the health system, but that of the economy as a whole. The prolongation of life expectancy is one of the

factors most closely associated with this challenge. In the United States, for instance, the cost of healthcare for people over the age of 85 is six times greater than in people aged 50 to 54 and twice as much as in the 75-79 age group (1).

There are different theories about how the increase in life expectancy relates to the burden of disease and its associated cost. *The expansion of morbidity* theory holds that the number of years humans will live with disease will increase (2), while the *compression of morbidity* theory (3) describes a scenario in which a gain in years of healthy life will lead to a postponement in disease and cost to more advanced life stages (i.e. they are compressed into that age segment). These different views have important social, political and economic implications. If, as a society, we invest resources to prolong the life of patients, this will expand their morbidity, while if we target risk and lifestyle habits we will probably delay and contract morbidity (4).

Regardless of how societies decide to meet the challenges associated with chronic diseases, any political or economic measure would need to take into account the fact that most of the costs are not associated with clinical services but with productivity losses (5, 6), and that expenditure on long-term care will represent an increasing proportion of healthcare costs in every economy, even in the most optimistic forecast models of cost containment (7). This will likely be compounded as the number of chronic diseases in the same person increases (8).

Despite the seriousness of the situation, neither organizations nor governments are decisively adopting measures to fight the chronic disease epidemic. Some consumer organizations do focus on the medical treatment of specific diseases, sometimes acting as pressure groups to increase investment in treatment, neglecting health promotion and disease prevention. Global donors are spending most of their funds on countering infectious disease and improving maternal and child health: very few resources are dedicated to countering chronic disease, and even fewer to tackling the challenges associated with polyopathy.

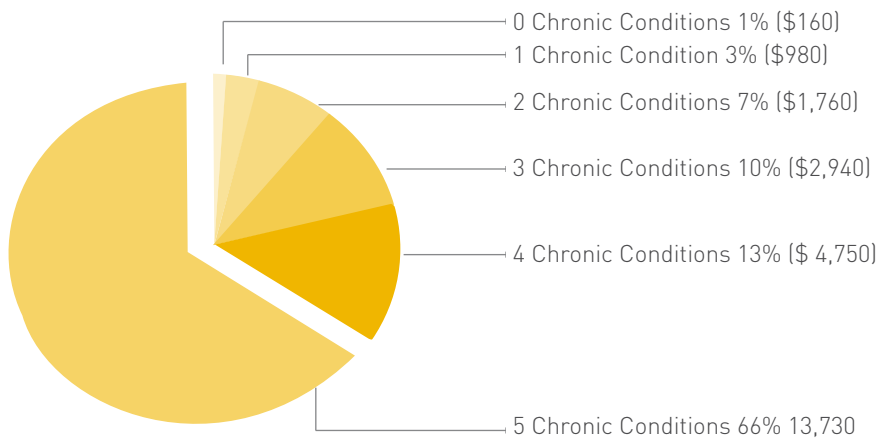
## What do we know?

Patients with five or more chronic conditions account for two thirds of the Medicare spend in the US (Figure 1). It has not been possible to find similar data from other countries, but it seems likely that the picture would be similar in other developed countries. In other

words, caring for patients with complex chronic disease is increasingly the main activity and the main cost for health services. As patients have more chronic conditions they are more likely to be admitted to hospital (Figure 2), often unnecessarily and incurring considerable cost. In the UK, a small number of patients, most of them frail elderly individuals with polypathology, accounts for a high proportion of unplanned hospital admissions (Figure 3). These admissions entail a considerable cost.

Figure 1

**Percent of medicare spending per person by number of Chronic Conditions (Average annual expenditure)**

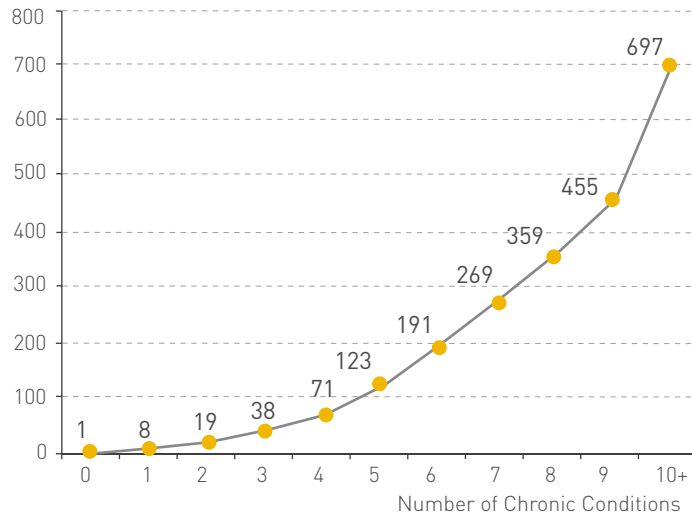


Source: Medicare Standard Analytic File. (9).



Figure 2

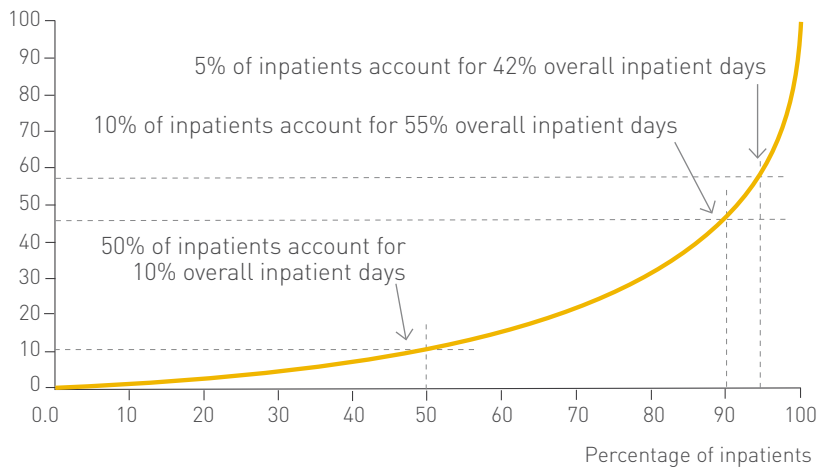
Unnecessary hospital admissions related to the number of conditions coexisting in a person



Source: Medicare Standard Analytic File (2001) (9).

Figure 3

A small percentage of patients account for many hospital bed days



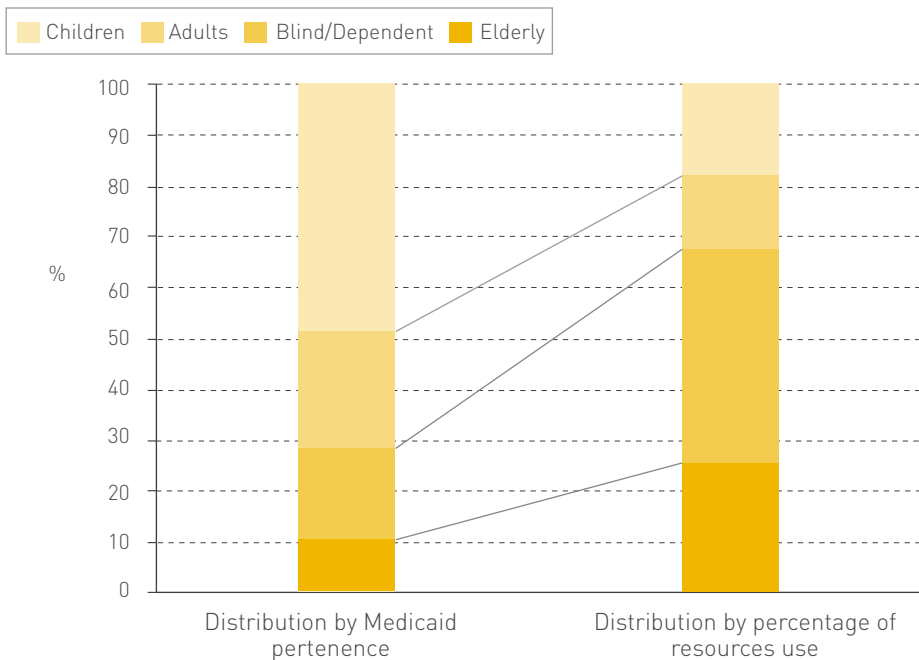
Source: Analysis of British Household Panel Survey (2001) (10).

Few studies are available on the cost of chronic illnesses for developing countries, and to our knowledge none evaluating costs associated with the management of patients with multiple chronic diseases (11).

In the United States care for people with chronic disease represents 70% of healthcare expenditure (12), but the associated loss of productivity due to disability, unscheduled sick leave, a decrease in effectiveness in the workplace, an increase in occupational accidents or negative impacts on work quality and customer care represent an even higher financial cost to countries than those related to healthcare services.

Figure 4

#### Distribution of Medicare Cover and Expenditure in Different Sectors of the Population



Source: Medicaid (13).

## Dependence associated with chronic diseases

In 2006 the WHO estimated that there were 650 million people with disabilities worldwide, representing 10% of the population (14). In the US it has been shown that disabled people account for most of the Medicaid budget despite representing a minority of cases (Figure 4) (13).

Most polyopathologies are associated with a high level of dependence, a concept which goes beyond disability in as much as it implies a person's need for support in order to perform ordinary everyday activities (as a result of physical, psychological, intellectual or sensory limitations). It has been estimated that people who are dependent as a result of chronic diseases represent about 2.5% of the total population (15).

A recent report by the Organization for Economic Co-operation and Development (OECD) highlights important levels of disparity among countries in terms of the amount of resources available to support dependent individuals, and a dearth of data on the economic scale of the services provided by family caregivers (16). The latter places a serious limitation on estimates of the costs associated with chronic diseases as it is widely recognized that most of the cost of caring for dependent people is assumed by family members (17). As the proportion of dependent people increases and fertility rates decrease, it is reasonable to expect a shift in this burden and its related costs from family members to the traditional system of health and social services (18, 19).

## Influence of lifestyles and disease risk factors on healthcare costs

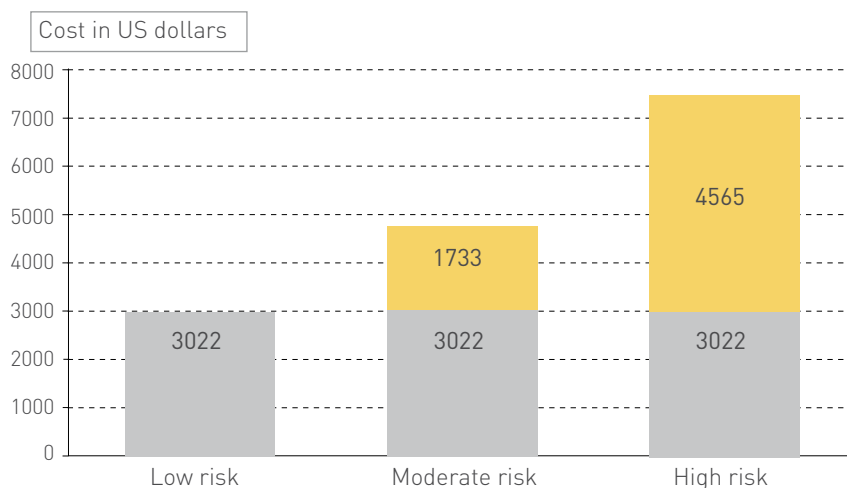
The prevalence of chronic diseases is closely related to unhealthy lifestyle habits (see Chapter 3). In the United States, the estimated cost represented by these habits in 2000 was (20):

- Smoking: 75.5 billion dollars in medical costs and 92 billion dollars associated with productivity losses (21).
- Obesity and excess weight (2002): 132 billion dollars (92 billion in direct costs and 40 billion in indirect costs) (22).
- Poor nutrition: 33 billion dollars derived from medical costs and 9 billion dollars of lost productivity as a result of cancer, cerebrovascular accidents and diabetes which can be attributed to bad nutrition ([www.cdc.gov/nccdphp](http://www.cdc.gov/nccdphp)).

One study found that these risk factors increase expenditure by 25% (23). Altogether, smoking, alcoholism, obesity and hypertension consume 1.5% of GDP in China and 2.1% in India (24). The cost increases with the number of health risk factors (Figure 5).

Figure 5

Estimated 2008 US Healthcare Cost per person by extent of risk factors (figures in US dollars)



Source: PricewaterhouseCoopers 2008 - World Economic Forum - Working Towards Wellness: The Business Rationale (25).

Healthcare costs are higher in people who are sedentary without being overweight than in obese people who are physically active (26). In Spain, two out of three children of school age and 38% of young people appear to be sedentary in their free time (27).

Interventions over lifestyles could have a big impact on expenditure on chronic diseases, essentially through weight reduction, improved nutrition, regular exercise, giving up smoking and early diagnosis and treatment (Chapter 3). Unfortunately, most countries around the world, and even organizations such as the WHO, allocate insufficient resources to health promotion and disease prevention. The latter, for instance, invested less than 8% of its budget in activities related to these two areas, and to mental health,

substance abuse and the management of chronic diseases (28). The early targeting of risk factors, whether through pharmacological or behavioral interventions, has many potentially positive effects (Table 1).

Table 1

Cost per Group of Countries per Quality-adjusted Life-year of Cholesterol and Hypertension Level Control Measures

INTERVENTION	Cost DALY saved (dollars) per group of countries		
	Very Low Income	Low Income	Average Income
Education and Mass-scale Measures	50-57	19-92	12-54
Voluntary reduction of salt	26-30	10-92	6-27
Compulsory salt reduction	34-78	14-114	9-15
Combination of education and compulsory salt reduction	31-48	31-48	7-23

Source: Murray et al. (2003) (29) Centers for Disease Control and Prevention. (2004) (30).

## What do we need to know?

Most of the questions related to the economic, social and political implications of multiple chronic diseases remain unaddressed (31).

### Economic implications

What are the total costs associated with the management of complex chronic diseases? The estimates must include data on healthcare costs, costs associated with productivity loss and disability, and to family care-giving for different combinations of diseases.

- What are the economic implications of different strategies for the provision of coordinated services (health and social) to people living with multiple chronic diseases?
- What is the most appropriate model of resource allocation across health promotion, disease prevention, healthcare and social service activities to minimize the economic and social impact of multiple chronic diseases?
- What interventions could reduce the productivity loss associated with multiple chronic diseases?
- What technological innovations could offer real, cost-effective alternatives to current care models?
- What is the impact of multiple chronic diseases on the lives of caregivers?
- What policies could lead to a reduction in the prevalence and the economic consequences of multiple chronic diseases?

## Social and political implications

- What is the impact of multiple chronic diseases on the lives of caregivers? What new roles, workflows and supportive services are needed to relieve their burden?
- What policies could lead to a large enough reduction in the prevalence and the economic consequences of multiple chronic diseases?
- Could key regions be transformed into living laboratories with the conditions necessary for the development, refinement, implementation and evaluation of innovative ways to optimize the management of polypathology?
- What strategies are needed to position the management of polypathology among the top priorities for leading political, academic, clinical, community and corporate organizations interested in the sustainability of the health system?

## What innovative strategies could fill the gaps?

Given the potentially devastating effects that multiple chronic diseases could have on the economy and on society at large, bold policies would need to be developed and implemented to facilitate the transformation of existing health and social services. Such

policies should at the least make it easier to fill most of the gaps identified in all of the preceding chapters, with an emphasis on:

- Efficient monitoring of the incidence, prevalence and impact of multiple chronic diseases (Chapters 1 and 2).
- Bold health promotion and disease prevention efforts at all levels (Chapter 3).
- The implementation of innovative models for complex chronic disease management, fostering leadership at the front line and bottom-up innovation (Chapter 4).
- The adaptation of existing health and social services to promote optimal integration and coordination of roles, workflows and processes at all levels (Chapter 6).
- The minimization of unnecessary suffering and the optimization of supportive care services throughout the entire natural history of multiple chronic diseases, and particularly at the end of life, for patients and their caregivers (Chapter 7).
- Strategies to engage people living with multiple chronic diseases and their caregivers in effective self-management programs (Chapter 5), demedicalizing their care as much as possible (Chapter 8).

Achieving this will not be easy. In fact, it could be argued that the slow nature of the policy-making process and the resistance to change that pervades all levels of the health system will hinder our ability to introduce the radical changes that are required to ensure that people living with multiple chronic diseases can achieve optimal quality of life without bankrupting the economy.

The jury is out. Let us hope that we have the foresight and courage necessary to bring about the creative partnerships among the government, academic institutions, the public and industry; the rigorous trans-disciplinary research and development work; the effective knowledge mobilization and management; and the level of political will needed to meet the unprecedented challenges created when we live long enough to accumulate multiple chronic diseases.

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### *Contributors*

Francisco Martos and Emilio Herrera wrote the first draft of this chapter in Spanish and approved its English translation. Alejandro Jadad revised the English translation extensively and approved it (with support from Francisco Martos) before its release for external contributions through the OPIMEC platform in both languages. Jaime Espín made important contributions, which Francisco Martos incorporated into a revised version of the chapter, which was approved by Emilio Herrera and the other contributors. This version was further revised by Richard Smith. Alejandro Jadad made some additional modifications to the text and approved the final version that was included in the paper-based book.

### *Acknowledgments*

Narcis Gusi made insightful comments on the chapter that did not lead to changes to its contents.

### *How to reference*

Martos F\*, Herrera E\*, Espín J, Jadad AR, Smith R. [\*Main contributors] Socioeconomic implications. 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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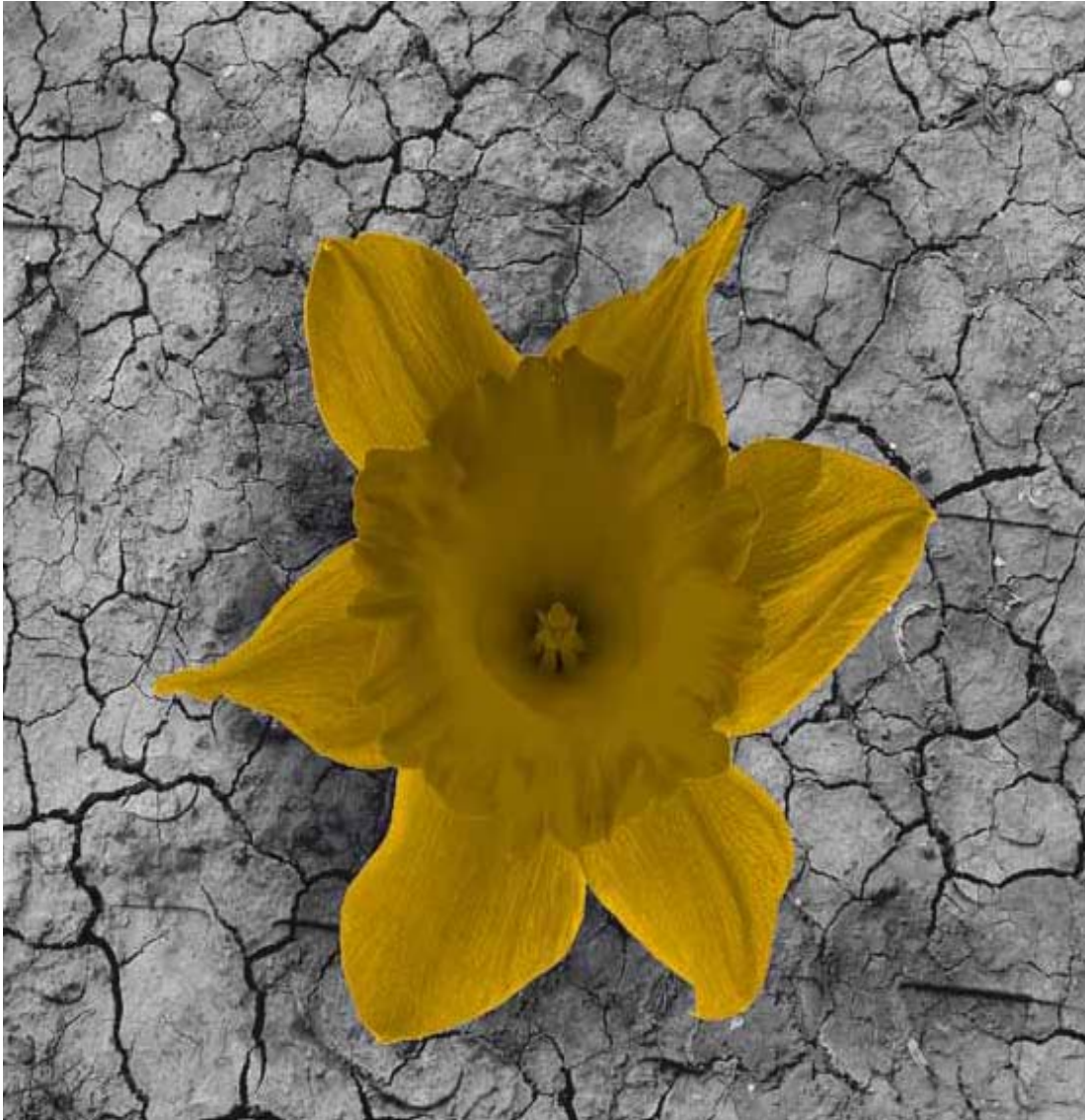
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## The promise of genomics, robotics, informatics and nanotechnologies

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

### Vignette: How it could be?

*Net-Log*

*Malaga (Spain), January 10, 2034.*

*Mixed emotions ravage my soul, if anything is left of it. I now remember almost everything, especially Laura, the most valuable piece of all that was seized from me.*

*I can no longer continue to evade the truth: I was solely responsible for the accident. I should never have driven in such heavy rain, knowing my own state of health. It is true that up to that point I had never suffered such a severe fainting episode. But on that day, of all days, I should have been more aware than ever of my limitations.*

*We were on our way to the hospital where I was to receive the Langerhan gene therapy that would finally revert my advanced state of deterioration. A new life, more time to share with her..*

*And then the emptiness... that inability to remember anything for more than 5 minutes, forcing all those around me constantly to introduce themselves. After the accident I also lost my sight, and they had to amputate a leg. A pacemaker, a hip replacement, hearing aids... I suppose I became a real monster for those around me. But perhaps I did have an inner consolation: my unawareness of what was happening. A living death.*

*But what am I now, truly? My eyes are nanocameras. My legs made of metal. My body is home to dozens of gadgets which regulate my blood flow. Even my mind is artificial. They call it a neo-hippocampus, and apparently it replaces a part of my brain that was damaged by the haemorrhage caused by the accident, or my illness, it doesn't matter. And what am I now? Man or machine? Or worse still, what percentage of me is human and how much is not? And my soul? Is that still human?*

*I suffer now. I suffer the absence of Laura, who was everything. And it may be that my new memory will not help much when I try to stop thinking about her. It would, unfortunately, seem to work very well. On the other hand, though, I must acknowledge that I have been able to meet my grandchildren. With my new eyes and new mind, I can enjoy being with them and then remember every minute together. Maybe I am no longer a burden to others. And maybe those flashes of happiness with my family more than make up for my suffering. I can now help others by recounting my experience in this Biographical Register of Well-being, shared with the whole world. Maybe that is what it means to be human now.*

## Summary

Have humans reached a turning point in their evolutionary journey? Have they been preparing the way throughout their history for the advances that will enable them to overcome or eliminate previously incurable illnesses this century? Will they reach immortality by the end of the 21<sup>st</sup> century?

The «scientific» approach to knowledge about the human body began with the observation of its inanimate anatomy on the dissection tables during the Renaissance, moving on to knowledge of the functioning of the organs, then the tissues, the cells and their organelles, finally leading to the decoding of DNA, which then opened the door to an era of promising technologies allowing the manipulation of our bodies at the molecular level. The same process has occurred in other fields, with reality being gradually broken down into its most basic elements. Whether this degree of progressive «unpacking» of our bodies will translate into everlasting health, and even immortality as some prominent scientists suggest, remains to be seen.

Regardless of where the ongoing scientific revolution leads, aggressive efforts are being made to conquer chronic diseases by harnessing the power of genomics, robotics, infonomics and nanotechnology. This technological foursome, also known as GRIN, is driving enthusiastic hordes of innovators to devote their energy and funds to the reverse engineering of existence, working back towards the artificial reconstruction of our very selves. Within this great field of integration, referred to by many as the «grand technological convergence of the 21<sup>st</sup> century», lie many potentially useful contributions to the fight against illnesses, in particular those currently considered incurable and chronic. These technologies also promise to re-shape the destiny of our species.

## Why is this topic important?

Throughout the final decades of the 20<sup>th</sup> century, with the decoding of the DNA, the seemingly unstoppable power of computers and the increased ability to manipulate matter at the molecular level, humans began to feel increasingly confident about their ability to eliminate disease and conquer death. At the dawn of the 21<sup>st</sup> century, however, it is not clear whether this will be possible. At this point, there are more questions than obvious answers, particularly in relation to what seems to be an 'inconvenient' adverse effect of our scientific and technological success since the Enlightenment: the high prevalence of chronic diseases, and the associated wave of poly-pathology.

Humans tend to consider themselves as the pinnacle of evolution, believing everything that has so far occurred has been programmed to result in them. However, it is also possible that humans are mere evolutionary specks moving along a trajectory that leads to a future without them. Given our capacity to create hugely powerful technological extensions to overcome most of our physical (and increasingly, cognitive) limitations, therefore, it is reasonable to ask: Are we simply transitional elements on the pathway towards a «post-human» species?

We have known since Darwin that the genetically best-endowed individuals are those with the greatest probability of surviving and reproducing. We humans have, however, succeeded to a great extent in interfering with the laws of evolution.

Today, the bearers of defective genes survive and reproduce thanks to scientific advances, allowing for an increase, even in cumulative terms, in the survival rates of specimens that will guarantee the presence of such genes in subsequent generations. Now, the children of diabetics and hemophiliacs may thus be able to live with both diabetes and hemophilia, and yet achieve life expectancy long enough to reproduce and to «gather» even more chronic conditions. Up until less than a century ago, this would have been unthinkable (1, 2).

As we tinker with nature, however, we are not only slowing down the «trimming» aspects of the evolutionary process, but also accelerating the process from an adaptive perspective. Genetic changes that would otherwise require thousands or even millions of years can today be implemented by means of simple techniques of manipulation at the laboratory or research centre of any moderately sized organization. We are now able to enhance the human body with modifications to an organic function by replacing pieces of DNA or by implanting biomedical devices.

Traditionally we have since childhood been taught that life is made up of four stages: birth, growth, reproduction and death. Given that most adults have their children before the age of 40, it would be easy to understand that with reproduction we fulfill our essential purpose, the survival of our genetic information as a species. From that point onwards, as happens with all other living beings, all we should have left is an alchemical rebalancing with the environment having reached our point of maximum entropy... our death. However, we human have pursued a different path. Thanks to the massive parallel computing power of our brains we have been able to embark on a relentless pursuit for immortality which is bringing us close to the point at which we might be able to surpass many of our most basic limitations (3): carbon-based units of weak bones surrounded by soft tissue, requiring narrow bands of pH and temperature, in the permanent presence of O<sub>2</sub>. Some even conceive a not-too-distant future in which our inventions exceed all of our capabilities, blurring the boundaries between human and machine, blending us into a new single entity, known as the Singularity (4).

This chapter deals with the main forces that seem to be driving such unprecedented evolutionary process at this point-genomics, robotics, informatics and nanotechnologies-which are collectively known as GRIN (Genomics, Robotics, Informatics and Nanotechnologies) (5).

## What do we know?

Instead of the traditional futuristic archetypes of humanoid robots collecting physiological information from us while using their free time to take care of household chores, technological trends are pointing in the direction of much more complex scenarios on which thousands of interconnected gadgets provide ubiquitous services (6). We are already seeing this through a plethora of projects that promote Ambient Assisted Living (AAL), an area that is receiving considerable attention in those regions of the world that register the longest life expectancy, such as Japan and the European Union (7, 8).

The following is a summary of what is happening in relation to each of the components of the GRIN movement.

### The G factor

Today it is already relatively straightforward to change the structure of a section of DNA in a laboratory, use a virus to introduce it into a cell and see if it performs a particular



function. This technological feat, however, has not been translated into the spectacular breakthroughs in the management of disease that were expected when the human genome was decoded. Although it would seem that this is just a question of time (9), it is possible that given the myriad elements that explain most of the chronic ailments affecting humans, regenerative medicine and gene therapy will only be successful at curing a handful of minor diseases, failing to produce the expected «silver bullets» that would correct the main sources of morbidity and mortality for single major diseases. The picture is even more dismal in relation to potential gene therapies for multiple chronic diseases.

## The R factor

There have also been impressive developments in robotic therapy (10). Nonetheless, the results are still falling short of the expectations of a few decades ago.

In *Metropolis*, the famous film of the 1920s directed by Fritz Lang, a futuristic society was divided into two castes, the thinkers and owners who lived on the surface, and the workers of the underground, laboring ceaselessly to maintain the pace of life of their masters. They ultimately come into conflict. Maria, the leader of the oppressed, is kidnapped by the masters and replaced by an android replica, with the aim of sowing chaos among the rebels. The humanoid image of this robot then became the popular archetype that has ever since inspired hundreds of researchers into artificial intelligence, viewing the replication of the human form as the logical path to the future. However, this descendant vision championed by many has been challenged with compelling arguments.

Many leading experts believe that we should promote the basic conditions required to allow artificial intelligent systems to evolve spontaneously, learning in a self-organized form, in the belief that once they have surpassed a certain threshold of information processing, intelligent behavior would emerge. The aim, then, would be an attempt to emulate what happens, for example, in colonies of termites, which are capable of manifesting the emergent intelligent behavior that allows them to construct sophisticated ventilation and storage systems, in a way that could not be explained by the arithmetic sum of their individual intelligences. In this case, the transfer of simple short-range chemical messages can generate highly precise coordinated reactions similar to that of neurons interacting through neurotransmission in their synapses.

As these two currently opposing strands evolve, an intermediate pathway represented by advances in so-called «human-machine interfaces» is evolving; the very same approach that has guided the development of tools capable of overcoming our limitations (e.g., pulleys, cars, planes, computers). Today, the boundary between biological and artificial is becoming blurred. Advanced surgical techniques are now beginning to be used to incorporate cybernetic creations as extensions to our own biological structures, bordering in many cases on what some still view as science fiction. Chronic conditions associated with the loss of limbs following accidents, in particular in traffic incidents and the workplace, are being managed with highly sophisticated controllable myoelectric prosthetics and re-nerivation techniques (11) which may soon incorporate haptic interfaces capable of providing a sense of touch. Cognitive robotic innovations are also being spurred on by advances in functional magnetic resonance imaging, which allows careful observation of neurological activity in areas affected by neurodegenerative conditions or by strokes.

## The I factor

Information and communications technologies represent more than simply another piece in the jigsaw being outlined here. They are essentially the glue that binds together the GRIN complex and underpins its potential.

The power of online social networks has been expressed clearly during natural disasters (12). As official information management systems were rendered ineffective by Hurricane Katrina, members of the public were able to generate, in a matter of hours, an online repository of resources and database of victims, allowing thousands of people to locate their relatives swiftly (13).

Similarly, many patients who were previously left to endure in solitude the daily consequences associated with chronic diseases are now beginning to join forces, supporting each other as «prosumers» (14, 15) or as e-patients (16).

In addition to the growing level of patient emancipation afforded by social networks, another powerful shift in the way in which humans create and manage knowledge is being brought about by hybrid webs or «mash-ups» (17). In essence, this involves something like «a pinch of this and a dash of that» in order to extract and blend different functional elements of disparate applications into a new set. As a result, it is now possible to blend electronic health records, large databases of demographic data, online maps and

powerful statistical tools to create dynamic spatial representations of the distribution of diseases in a population, and their associated risk factors (18).

Another wave of change is being nurtured by the unprecedented wave of technological convergence that is ushering in the age of mHealth (mobile health), heralded by mobile telecommunication devices connected to the Web. This is leading to the emergence of powerful telehealth solutions designed to improve the quality of life of people living with chronic diseases and to optimize the use of limited resources (19).

Unfortunately, little is known about the value of this veritable renaissance in reducing suffering for people living with multiple chronic diseases.

## The N factor

Nanotechnologies, which allow the manipulation of matter at its smallest scale, are giving birth to an area already known as «Nanomedicine», a hybrid of the physical and biological sciences that promotes the interaction between the human body and different materials, structures or devices which operate on a nanometric scale.

The most important aspect of nanotechnologies lies not only in the manipulation of matter itself, but the potential derived from the radical change undergone by the physical and chemical properties of matter when working at such a scale (20): electrical conductivity, color, resistance or elasticity (21).

At present, the application of nanomedicine focuses on three major transversal strands, irrespective of the pathology being targeted (22):

- *Nanodiagnosis*, comprising the development of analysis and imaging systems designed to detect illnesses at the earliest possible moment, both in vivo and in vitro. A promising area of work focuses on nanobiosensors (21), minute tools that combine **biological receptors** (a cell, a fragment of DNA or protein) capable of detecting the presence of a substance, with **sensors or transducers** capable of measuring any related reactions.
- *Nanotherapy*, the controlled release of drugs, through systems able to deliver drugs exclusively to the affected areas or cells in the body, in the hope of achieving maximum therapeutic effects with minimal or no adverse events. Exciting work is being conducted on innocuous biodegradable nanoparticles (23) which can carry drugs and then be effectively eliminated by the kidneys once they have performed their task (24).

- *Nanoregeneration*, the purpose of which is to repair or replace damaged organs or tissues. Carbon nanotubes (25), for instance, are being created to build replacement limbs with levels of performance that exceed those of their natural counterparts.

Unfortunately, the knowledge available on the role that nanotechnologies play in the management of multiple chronic diseases is scant.

## What do we need to know?

Some of the key questions requiring careful consideration (although they may be unanswerable) are:

- Are multiple chronic diseases the inevitable price that we must pay for our greater longevity?
- Does the level of complexity associated with most multiple chronic diseases exceed the capacity of GRIN technologies to offer tangible solutions?
- Even if we could eliminate chronic diseases through GRIN technologies in the mid to long term, will we be able to use innovations to mitigate their impact in the short term?

## What innovative strategies could fill the gaps?

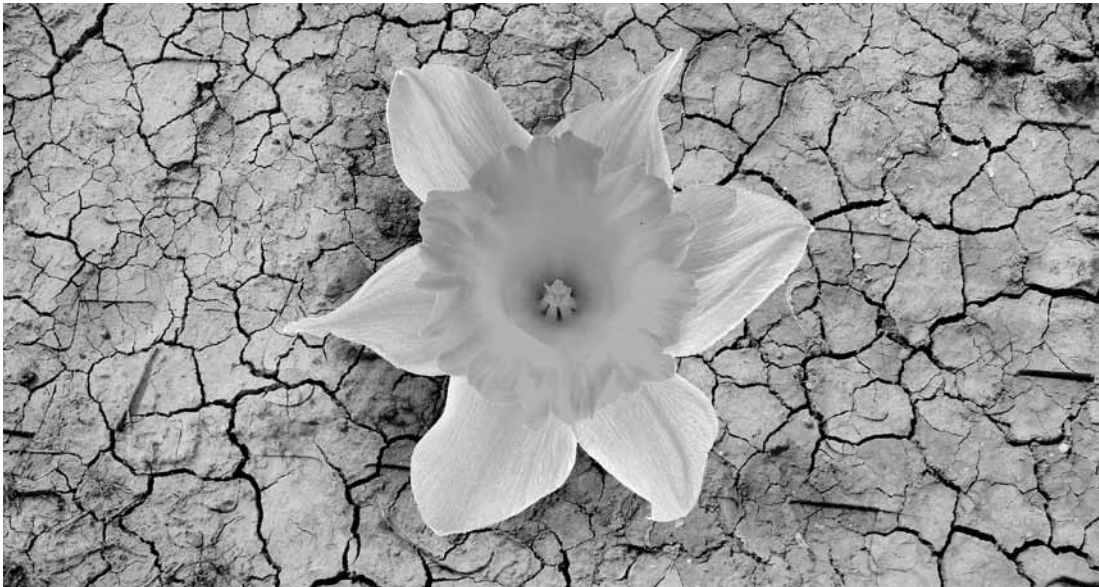
Harnessing the power of emerging GRIN technologies will require a careful balance between the inevitable super-specialization inherent in them and the need to create system-wide responses to the challenges associated with multiple chronic diseases. It will as a result be necessary to nurture truly inter-disciplinary skills among clinicians, policymakers and managers.

It will also be essential to develop «bridge technologies» and powerful incentives to promote the efficient flow of knowledge across the boundaries of each of the technological domains. Knowledge management tools and managers will thus act as the central pillar of the sustainable reuse of information, the average lifespan of which will continue to shorten.

In addition, new business models and ethical frameworks will be needed to bridge, in radical ways, the gap between bench and society, enabling real-enough-time adoption of scientific breakthroughs.

New methodologies will also be essential to enable clinicians, managers, policymakers and the public to make informed decisions at a speed that can match the pace of technological innovation (26).

For GRIN technology theorists, humans will soon be able to gain more than a year of life expectancy in each chronological year, thus bringing immortality within reach before the end of the 21<sup>st</sup> century. Others believe that the same technological prowess that gave birth to GRIN technologies has given us the capacity to destroy our very sources of survival, thus turning us into a suicidal species unlikely to survive to see the end of this same century (27, 28). As the future is impossible to predict, all we can do at this point is hope for the best, while being as receptive as possible to innovations that could help relieve the pain, anxiety, fear, sadness and despair caused by multiple chronic diseases. As for the remainder... we shall see.



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### *Contributors*

Julio Lorca wrote the first draft of this chapter in Spanish and approved its English translation. Alejandro Jadad reviewed the English translation and edited it extensively.

Responsibility for the content rests with the main contributor and does not necessarily represent the views of Junta de Andalucía or any other organization participating in this effort.

### *Acknowledgments*

Visitors to the OPIMEC platform made no comments to the chapter.

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## Dealing with the challenges of polypathology, together: What's next?

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

In March of 2009, we wondered if it would be possible to co-create a book on polypathology, within a year, from scratch, with volunteer contributors from all over the world, using online social media and with no financial incentives.

Well, we did it!

Once the lead contributors produced the first version of each of the chapters, and they were reviewed by an editor-guarantor (ARJ), we embarked on a massive e-mail campaign to reach potential contributors (1). The outgoing messages, which were sent in 17 waves, were adapted to the language, area of interest and contents of each of the message recipients.

Between December of 2009 and March of 2010, 550 people were targeted. They included not only experts suggested by lead contributors, but also the corresponding authors of articles that had been selected as references in the initial versions of the chapters.

In addition to the e-mail outreach efforts, we included banners on key websites of the Andalusian School of Public Health (2) and the Andalusian Ministry of Health (3), and in the blogs of two of the lead contributors (4, 5). We also optimized the contents of the OPIMEC platform for top search engines and created a space on Facebook describing the project and inviting participation.

During the four months in which the chapters were available for contributions, the OPIMEC site received more than 13,000 visits from people in 80 different countries. Of these visitors, 55 people from 18 countries made 235 contributions to the chapters. The

theme that received most comments was health promotion and prevention (Chapter 3), with over 40% of the contributions, followed by patient education and self-management with 10% (Chapter 5).

By the end of March of 2010, all of the draft chapters had been reviewed at least twice by one or more of the editors. By the time of the launch, in early June of 2010, the entire edited version was available as a free hard copy or in portable document format (PDF), for free download (6). Each of the chapters will also continue to be available through [www.opimec.org](http://www.opimec.org), as a «live» version, enabling continuous updates and improvements.

## What did we learn during the process?

We gained valuable insights during the co-creation of the book, particularly in relation to the use of online collaborative tools and the engagement of experts in the process.

The following lessons are worth highlighting, as they may be useful to those interested in embarking in similar exercises:

- Technological glitches are unavoidable: At times, we faced technological problems with the tools that we used to facilitate content co-creation, which made the process frustrating to the editorial group, to the support team and to the volunteers who were willing to contribute to the book. Along the way, some contributors found such glitches unacceptable and decided to give up, despite having a help line available as well as the option to make contributions through e-mail at any time. We hope that these colleagues will be keener to join the project in the future, and that they understand that, as they continue to evolve, information and communication technologies will continue to present challenges to early adopters.
- It is difficult to match versions of the same document as they evolve in multiple languages at a different pace: To make facilitate this process, we produced the initial version of the book in English, translating and incorporating contributions in Spanish as they emerged. Throughout the process, however, all comments were visible in both languages in the corresponding section of the chapter.
- Firm deadlines for contributions must be set and enforced: This was perhaps the greatest challenge, as prominent colleagues pleaded to have additional time to provide their input. Instead of jeopardizing the overall project by extending the timelines, we thanked those interested and reiterated that their contributions would

be welcome, at any time, as the book would continue to evolve on the OPIMEC platform, as a living entity.

- It is essential to have a clear common goal, a diverse editorial group, and institutional support: By starting with 10 clearly defined topics, we could enlist leading contributors quickly. Having a strong and diverse editorial group enabled us to distribute functions in a way that made the workload manageable throughout the process, while building on individual areas of strength. Thanks to the strong backing from the Andalusian Ministry of Health, we could set the date for the book launch during Spain's presidency of the European Union. This acted as a strong incentive and justification for the contributions to be made within the established deadlines.
- Copyleft and contributorship are viable options: This book is a living proof that it is possible to motivate a large group of experts to embrace «copyleft» (7) and «contributorship» (8), as viable alternatives to their more restrictive siblings, «copyright» and «authorship».

## Now, what? Are we ready to meet common challenges, together?

The use of a standardized structured format, with key questions as the main drivers for content development in all chapters, also paid off. The book not only provides easy access to the best available knowledge on 10 major aspects of polypathology but also a long list of unaddressed questions and issues that require urgent attention.

We feel that the collaborative work that resulted in this book could easily become the foundation for joint projects that could fill many of the identified gaps, in record time.

The following are some examples of questions that could drive the design, execution and dissemination of large-scale collaborative projects through which we could attempt to meet the challenges created by polypathology, at all levels:

- Is it possible to promote an ongoing global survey to monitor polypathologies in different regions of the world simultaneously?
- Is it possible to create a taxonomy that could facilitate the exchange of knowledge and the evaluation of innovations for the management of polypathology worldwide?

- What strategies or interventions are needed to facilitate the development of the knowledge base, attitudes, skills and behaviours required by professionals to bridge social and health services in a way that would contribute to meeting the unmet methodological, technological, management, social, political and economic needs associated with polypathology?
- Are polypills cost-effective interventions for polypathologies? If so, how can their widespread use be encouraged?
- Is it possible to design, implement and evaluate a flexible model of care that brings together the power of de-centralized innovation and leadership by front-line professionals and the public, with the efficiency of a centralized policy-making and management structure?
- Is it feasible to use online social media to create and sustain a global network of self-management and peer-to-peer resources for people living with multiple chronic diseases?
- What are the new functions or whole occupations or the new roles for existing occupations that are required to bridge or blend social and health services in a way to that would meet the needs of people living with multiple chronic diseases and their caregivers?
- To what extent could effective innovations for the management of polypathology be adopted and adapted across different regions of the world?
- How do different combinations of diseases or disease trajectories influence the supportive and palliative care needs of people with polypathologies and their caregivers?
- What is the impact of multiple chronic diseases on the lives of caregivers? What new roles, workflows and supportive services are needed to relieve their burden?
- Could Integrative Medicine promote the demedicalization of the management of polypathologies? Could it promote greater acceptance, among patients and caregivers, of the unavoidable suffering associated with multiple chronic diseases and the ageing process?
- What are the total costs associated with the management of polypathologies?
- Does the level of complexity associated with most polypathologies exceed the capacity of GRIN technologies to offer tangible solutions?

- Could key regions be transformed into living laboratories with the conditions necessary for the development, refinement, implementation and evaluation of innovative ways to optimize the management of polypathology?
- What strategies are needed to position the management of polypathology among the top priorities for leading political, academic, community and corporate organizations interested in the sustainability of the health system?

Answering these questions, and many others that remain unaddressed, will not be easy. It will require a very creative blend of public engagement; creative partnerships among the government, academic institutions, the public and industry; rigorous trans-disciplinary research and development; strong input from social and political scientists; visionary technological innovation; effective knowledge mobilization and management; and extraordinary political will.

Such effort will require unprecedented levels of generosity to overcome the powerful perverse incentives that have made us so vulnerable to polypathology.

We have already proven, by co-creating this book through OPIMEC, that we can work across traditional boundaries, contributing to a common ambitious agenda. We must now scale up the level of our commitment to create and implement the potent interventions that are required to overcome the apparently insurmountable challenges we face, together.

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### *Contributors*

Andrés Cabrera wrote the initial draft of this chapter in Spanish. Alejandro Jadad wrote the last version and translated it into English. This chapter received contributions from Begoña Isac, Diana Gosálvez, Alejandro López and Antonio J. Contreras (in Spanish).

Responsibility for the content rests with the main contributors and does not necessarily represent the views of Junta de Andalucía or any other organization participating in this effort.

### *Acknowledgments*

Book editors and contributors.

### *How to reference*

Cabrera A\*, Jadad AR\*, Isac B, Gosálvez D, López A, Contreras AJ. [\*Main contributors]. Dealing with the challenges of poly pathology, together: What's next? 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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# When people live with multiple chronic diseases: a collaborative approach to an emerging global challenge

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