When people live with multiple chronic diseases: a collaborative approach to an emerging global challenge
Words cloud from chapter sections “Why is this topic important?” and “What do we know?”
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When people live with multiple chronic diseases:
a collaborative approach to an emerging global challenge

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Contents

Foreword

Chapter 1 Why Multiple Chronic Diseases? Why now? What is going on around the world? 19

Chapter 2 The language of polypathology 39

Chapter 3 Prevention and health promotion 59

Chapter 4 Management models 89

Chapter 5 Patient education and self-management support 117

Chapter 6 Primary care, institutional services and integrated management processes 143

Chapter 7 Supportive and palliative care 163

Chapter 8 Integrative medicine 191

Chapter 9 Socioeconomic implications 213

Chapter 10 The promise of genomics, robotics, informatics and nanotechnologies 229

Chapter 11 Dealing with the challenges of polypathology, together: What’s next? 243

Abbreviations 250

Figures and Tables 251

Index 252
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.»
In the last four lines, Sappho refers to a myth that was very popular in the 7th 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 21st 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 20th 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.
### Search strategy

**ORGAN-SYSTEM**

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Database: Ovid MEDLINE[R] <1950 to April Week 1 2009>.

One of the main messages from the patchy literature is that the estimates of the prevalence of polypathology 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 polypathology 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 polypathology 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 polypathology of 91% was also found in a sample of indigent, predominantly African-American patients in the United States [20].

As expected, the prevalence of polypathology 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 polypathology 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 polypathology 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 polypathology 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:
<table>
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<th>7.</th>
<th>Examine best practices in patient-physician communication strategies for care management decisions for patients with MCCs or with social complexity:</th>
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<tr>
<td>• What are best methods for eliciting patients with preferences in light of care complexity, and engaging patient social support structures (e.g. family)?</td>
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<th>8.</th>
<th>Evaluate new Health Information Technology strategies to support complex care management to advance knowledge of:</th>
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<tr>
<td>• What decision support tools are needed for patients with complex care needs?</td>
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<td>• How can patient registries best support care management for patients with MCCs?</td>
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<td>• What type of Patient directed HIT tools can be developed for optimizing self-management for such patients?</td>
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| 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 polypathology.

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. 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 polypathology (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 polypathology, 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).
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.
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 Kulusk, 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
References


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

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>AAL</td>
<td>Ambient Assisted Living</td>
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<tr>
<td>BMJ</td>
<td>British Medical Journal</td>
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<tr>
<td>CAM</td>
<td>Complementary And Alternative Medicine</td>
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<td>CCD</td>
<td>Complex Chronic Disease</td>
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<tr>
<td>CCM</td>
<td>Chronic Care Model</td>
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<tr>
<td>CIRS</td>
<td>Chronic Illness Resources Survey</td>
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<td>CMPs</td>
<td>Case Management Programs</td>
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<tr>
<td>CVD</td>
<td>Cardiovascular Disease</td>
</tr>
<tr>
<td>DMPs</td>
<td>Disease Management Programs</td>
</tr>
<tr>
<td>EASP</td>
<td>Escuela Andaluza de Salud Pública</td>
</tr>
<tr>
<td>EPP CIC</td>
<td>Expert Patients Programme Community Interest Company</td>
</tr>
<tr>
<td>GRIN</td>
<td>Genomics, Robotics, Informatics and Nanotechnologies</td>
</tr>
<tr>
<td>ICCC</td>
<td>Innovative Care for Chronic Conditions</td>
</tr>
<tr>
<td>ICD</td>
<td>International Classification of Diseases</td>
</tr>
<tr>
<td>ICED</td>
<td>Index of Coexisting Disease</td>
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<td>IDS</td>
<td>Individual Disease Severity</td>
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<tr>
<td>MCCs</td>
<td>Multiple Chronic Conditions</td>
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<tr>
<td>MD team</td>
<td>Medical Doctor</td>
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<tr>
<td>MeSH</td>
<td>Medicines Medical Subject Headings</td>
</tr>
<tr>
<td>MI</td>
<td>Motivational interviewing</td>
</tr>
<tr>
<td>MPOWER</td>
<td>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]</td>
</tr>
<tr>
<td>NHIS</td>
<td>National Health Interview Survey</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service</td>
</tr>
<tr>
<td>OECD</td>
<td>Organization for Economic Co-operation and Development</td>
</tr>
<tr>
<td>OPIMEC</td>
<td>Observatorio de Prácticas Innovadoras en el Manejo de Enfermedades Crónicas Complejas</td>
</tr>
<tr>
<td>PACE</td>
<td>Program of All-inclusive Care</td>
</tr>
<tr>
<td>QALY</td>
<td>Quality-Adjusted Life Year</td>
</tr>
<tr>
<td>QRISK</td>
<td>Cardiovascular disease risk score</td>
</tr>
<tr>
<td>RE-AIM</td>
<td>Reach, Effectiveness, Adoption, Implementation and Maintenance</td>
</tr>
<tr>
<td>SNOCTM</td>
<td>Systematized Nomenclature of Medicine-Clinical Terms</td>
</tr>
<tr>
<td>SSPA</td>
<td>Sistema Sanitario Público de Andalucía</td>
</tr>
<tr>
<td>TCAM</td>
<td>Traditional Complementary And Alternative Medicine</td>
</tr>
<tr>
<td>TPE</td>
<td>Therapeutic patient education</td>
</tr>
<tr>
<td>VHA</td>
<td>Veterans Health Administration</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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</tbody>
</table>
Figures and Tables

Chapter 1

Figure 1. Search strategy 20
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 23
Figure 3. Interactive table of contents with a section simple 29

Chapter 2

Figure 1. Baseline Functional Impairment (measured on the Barthel scale) at Admission and Discharge of General and Pluripathological Patient Cohorts 44
Table 1. Criteria which define the Pluripathological Patient 41
Table 2. Modified Charlson Index 47
Table 3. Cumulative Illness Rating Store 48
Table 4. Kaplan-Feinstein Comorbidity Index 50

Chapter 3

Figure 1. Effectiveness of Various Forms of Nicotine Replacement Therapy in Helping People to Stop Smoking 63
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 70
Table 1. A Systematic Review of Interventions Designed to Improve the Diet and Promote Physical Activity 66
Table 2. Requirements for an Effective Screening Programme 74
Table 3. UK Criteria for Appraising the Viability, Effectiveness and Appropriateness of a Screening Programme 75
Table 4. Systematic Population Screening Programmes which have not been Recommended in the UK 78

Chapter 4

Figure 1. The Chronic Care Model 91
Figure 2. The Expanded Chronic Care Model 91
Figure 3. WHO, Innovative Care for Chronic Conditions Framework 93
Figure 4. Kaiser Permanente risk stratification pyramid 97
Figure 5. The linear process of planned change 103
Table 1. Key elements of the ICCC model 92
Table 2. Effective interventions in the management of chronic patients 101

Chapter 8

Table 1. CAM Treatments Based on Sound Evidence 195

Chapter 9

Figure 1. Percent of medicare spending per person by number of Chronic Conditions 214
Figure 2. Unnecessary hospital admissions related to the number of conditions coexisting in a person 215
Figure 3. A small percentage of patients account for many hospital bed days 215
Figure 4. Distribution of Medicare Cover and Expenditure in Different Sectors of the Population 216
Figure 5. Estimated 2008 US Healthcare Cost per person by extent of risk factors 218
Table 1. Cost per Group of Countries per Quality-adjusted Life-year of Cholesterol and Hypertension Level Control Measures 219
Index

Assessment tools 45
Associated factors 22
Bottom up 104
CAM Treatments 195
Cardiovascular Event 70
Case management 96
Category 41
CCM 90, 95
Challenges 241, 243
Charlson Index 98
Children 22
Chronic care management 100
Chronic Care Model 91
Chronic diseases 18, 19, 45, 90
Chronic patients 101
CIRS Scale 47
Collaborative effort 24, 243
Community 68, 200
Community self-management 129
Comorbidity 39
Complex adaptive systems 102
Complex chronic care needs 23
Complex chronic cases 95
Complex chronic disease 45
Confluent morbidity 45
Contributor, contributorship 29
Cooperation 102
Customization 175
Death 166, 168, 169
Demedicalization 199
Dependence 217
Developing countries 22
Diet 65
Disease burden 45
Disease risk factors 217
Dying phase 168
Economic implications 198, 211, 219
End of life 164, 167
Entrepreneurship 104
Environment 67
EPP CIC 130
Evercare model 99
Expanded Chronic Care Model 90
Flinders Program 124
Functional deterioration 44
G factor 230
Genomics 227
Guided Care Model 96
Guided Mastery 126
Health care professionals 121, 125
Health Promotion 57
Healthcare costs 217, 218
Hospital 215
I factor 232
ICCC 92
ICCC model 92, 93, 101
ICD 98
ICED 48
Illness rating store 48
Individuals 69
Informatics 227
Innovative strategies 51, 82, 102, 129, 149, 175, 201, 220, 234
Institutional services 141
Institutions 166
Instruments 50
Integrated care processes 103
Integrated management processes 141
Integration 129
Integrative medicine 189, 198, 200
Kaiser model 96
Kaiser Permanente risk stratification pyramid 97
Kaplan-Feinstein Comorbidity Index 50
Kaplan-Feinstein Index 49
Leadership 104, 105
Levels, prevention 60
Lifestyles 217
Managed care 145
Management models 87, 90
Management of patients 23
Mass media 67
Medicare 214, 216
Metrics 22
Mortality 18
Motivational Interviewing 122
Multiple 19
Why Multiple Chronic Diseases? Why now? What is going on around the world?
Words cloud from chapter sections “What do we need to know?” and “What innovative strategies could fill the gaps?”

[Available at: http://www.wordle.net]
When people live with multiple chronic diseases:
a collaborative approach to an emerging global challenge

This book is continuously evolving at www.opimec.org