

When people live with multiple chronic diseases: lessons from the use of a social media to promote global collaborative efforts*

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Abstract: While public health and modern medicine contributed to a dramatic increase in life expectancy in the 20th century, the downside of this success has been an epidemic of chronic, incurable diseases, which now account for more than 80% of deaths worldwide. This epidemic has created yet another new phenomenon: a growing number of people are living with multiple chronic diseases at the same time, having to cope with them within out-dated, disconnected and unprepared healthcare delivery systems that continue to focus on acute care of curable diseases, or on single conditions that affect individual organs or systems. On June 1, 2010, as part of Spain's Presidency of the European Union, the Andalusian government launched the first co-created, interactive, living and global book on the main challenges faced by people who live with multiple chronic diseases. The book, which received input from every inhabited continent, was co-created with support from free social resources available through the Global Observatory of Innovative Practices for Complex Chronic Diseases (known in Spanish as OPIMEC and available at www.opimec.org). The book, and the live content available at OPIMEC, summarizes the best available knowledge on this important and seriously neglected area, and proposes 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. It also lists key questions that remain unanswered, and that could be tackled by teams of individuals supported by the platform. The knowledge created by this global community is available to anyone with access to the Internet, free of charge, in English and Spanish, and will continue to evolve through the Observatory, where anyone interested in multiple chronic diseases and Internet access could make contributions at any time, from anywhere.

Keywords: Chronic disease; polypathology; social media; collaboration; web 2.0; Internet; Web; disease management

*"In this fallen world everything good has unintended evil consequences, every Yang has a Yin."*¹

1. Introduction: Why multiple chronic diseases? Why now?

The extraordinary level of control of acute conditions and the resulting lengthening of life expectancy achieved by humans in the 20th century is now ushering a global epidemic of chronic diseases and infirmity.

The World Health Organization (WHO) estimated in

2005 that 60% of deaths around the world were already due to chronic diseases, with 80% of the total occurring in low to middle income countries². 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 narrowing³. To compound this, depression and not physical injuries, is now the leading cause of years lost to disability in the world⁴.

Sadly, this epidemic, which has been the subject of many recent reports⁵, is being underestimated and neglected⁶. It is also creating a new phenomenon: a growing number of people are living with multiple chronic diseases.

*This article was produced by copying and blending text from the initial and final chapter of the book 'When people live with multiple chronic diseases: a global collaborative challenge', which is available, free of charge, at www.opimec.org

This phenomenon, known as ‘polypathology’, includes not only those with an “index disease” that triggers 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).

People with polypathology may represent 50% or more of the population living with chronic diseases, at least in high-income countries^{7,8,9}. As expected, the prevalence of polypathology seems to progress with age, with the proportion of people who live with three or more chronic conditions increasing 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 more¹⁰. The economic impact of polypathology, although largely unknown, is likely to be large. In the United States it is estimated that people with multiple chronic diseases already consume two thirds of health funds, with those with five or more chronic diseases being responsible for 80% of Medicare expenditures¹¹.

Not surprisingly, data on the prevalence and impact of polypathology from low and middle countries, or on children or adolescents are sparse too.

2. Could a global community be created around the challenges of polypathology?

Throughout the successful development of a region-wide process to transform the management of polypathologies, released in 2002, and its subsequent release and implementation, the leaders of the Andalusian Ministry of Health in Spain became aware of the almost complete absence of meaningful collaboration among leading groups making contributions in this area throughout the world. 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 that are needed to meet the needs of those living with multiple chronic diseases.

In 2006, they also realized that 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 in Spain 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 complex chronic diseases 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 complex chronic diseases (supported by online social networking tools)

In March of 2009, the Ministry 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 10 poorly-understood areas related to complex chronic diseases that they felt could benefit by international collaborative initiatives:

- Epidemiological issues
- Prevention and health promotion
- The language of poly-pathology and assessment of complexity
- Disease management models
- Patient education and self-management
- Primary care and integrated management processes
- Supportive and palliative care
- Demedicalization of care
- 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 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.

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

3. What happened?

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*, and a team to support editors and contributors had been constituted.

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 the general public (e.g., through a lay summary)
- Disclosed their affiliation with organizations that may have an interest in the management of CCDs 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 relate to their professional activities or organizational goals, be them 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?*

* Dr. Renee Lyons joined the editorial group at the end of 2009

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? So what?*

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 exists 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 (technological, financial and human) needs 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 (PM) supported contributors writing in Spanish and another (ARJ, the Editor-in-Chief and convener of OPIMEC) 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 alternative language, the same bilingual senior editor (ARJ) 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 improve-

ment.

While the chapters were being uploaded, the editors and lead contributors produced a list of peers that they thought could provide useful comments on each of the drafts, selecting them among colleagues they knew or among 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’¹².

After a minimum of a month since 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 ARJ in English, and PM, AC and ARJ 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 contributors¹³.

Between December of 2009 and March of 2010, 550 experts suggested by lead contributors or corresponding authors of articles that had been selected as references in the initial versions of the chapters were targeted.

In addition to the e-mail outreach efforts, we included banners on key websites of the Andalusian School of Public Health and the Andalusian Ministry of Health, and in the blogs of two of the lead contributors. 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 during 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, with over 40% of the contributions, followed by patient education and self-management with 10%.

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 through the OPIMEC platform [www.opimec.org], where each of the chapters will also continue to be available, as a “live” version, enabling continuous updates and improvements.

In summary, the effort 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 people in every society in the world.

4. 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, and the online interactive content on OPIMEC not only provide 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.

The collaborative work, which is available to anyone free of charge (thanks to copyleft licensing), 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?
- 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

¹ The names of all contributors appear listed under the title of each chapter and in the table of contents

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?

- How does polypathology link with other areas such as caregiving, aging well or complexity where the approach has been to enter through a specific condition such as diabetes, stroke or Alzheimer's?
- 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 health professions or the new roles for existing health professionals that are required to 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 man-

agement 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 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. There are other, more generic, unaddressed challenges, particularly in relation to the lack of familiarity with online tools and processes for knowledge co-creation, the limited amount of incentives to promote international collaboration, and the poor recognition that polypathology has within a system that continues to focus on individual diseases, organs or systems.

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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References

- [1] Boyd JH. Are Americans Getting Sicker or Healthier? *Journal of Religion and Health* 2006; 45:559-585
- [2] World Health Organization: Global Report. Preventing Chronic Disease: a vital investment. 2005 [http://www.who.int/chp/chronic_disease_report/en/]
- [3] Fuster V, Voute Janet. MDGs: Chronic diseases are not on the agenda. *Lancet* 2005; 366: 1512-4
- [4] World Health Organization: Depression [http://www.who.int/mental_health/management/depression/definition/en/]
- [5] World Health Organization: Chronic Diseases [http://www.who.int/topics/chronic_disease/en/index.html]

- [6] Horton R. The neglected epidemic of chronic disease. *Lancet* 2005; 366: 1514
- [7] Fortin M, Dionne J, Pinho G, Gignac J, Almirall J, Lapointe L. Randomized controlled trials: do they have external validity for patients with multiple comorbidities? *Annals of Family Medicine* 2006;4:104-8
- [8] Anechino C, Rossi E, Fanizza C, De Rosa M, Tognoni G, Romero M; working group ARNO project. Prevalence of chronic obstructive pulmonary disease and pattern of comorbidities in a general population. *International Journal of COPD* 2007; 2: 567-74
- [9] Kahn LS, Fox CH, Olawaiye A, Servoss TJ, McLean-Plunkett E. Facilitating quality improvement in physician management of co-morbid chronic disease in an urban minority practice. *Journal of the National Medical Association* 2007;99: 377-83
- [10] Walker AE. Multiple chronic diseases and quality of life: patterns emerging from a large national sample, Australia. *Chronic Illn.* 2007; 3(3): 202-218
- [11] Chronic care: making the case for ongoing care. Robert Wood Johnson Foundation, 2010 [www.rwjf.org/pr/product.jsp?id=50968]
- [12] Smith R. Authorship is dying: long live contributorship. *BMJ* 1997; 315: 696 [<http://www.bmj.com/cgi/content/full/315/7110/696>].