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

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The language of polypathology

This chapter is continuously evolving at 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 21st 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 polypathology, 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 comordibity 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)

CATEGORY A
Heart failure which, in a clinically stable situation, has been classified as grade II by the NYHA[1] (symptoms associated with everyday physical activity)
Ischemic heart disease
CATEGORY 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[2], which has lasted for at least 3 months
CATEGORY C
Chronic respiratory disease which, in a clinically stable situation, has been associated with: MRC grade 2 dyspnea[3] (breathlessness at normal walking pace on level ground), or FEV1<65% or SaO2 ≤ 90%
CATEGORY D
Chronic inflammatory intestinal disease
Chronic liver disease with portal hypertension[4]
CATEGORY E
Cerebrovascular accident
Neurological disease with permanent motor deficits which cause limitations in basic everyday activities (Barthel Index below 60)

CATEGORY E (continued)
Neurological disease with permanent cognitive deterioration, which is at least moderate (Pfeiffer Scale with 5 or more errors)
CATEGORY F
Symptomatic peripheral arterial disease Diabetes mellitus with proliferative retinopthy or symptomatic neuropathy
CATEGORY G
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
CATEGORY H
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 polypathology 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 polypathological 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 polypathologies 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 polypathologies 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 polypathological 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).

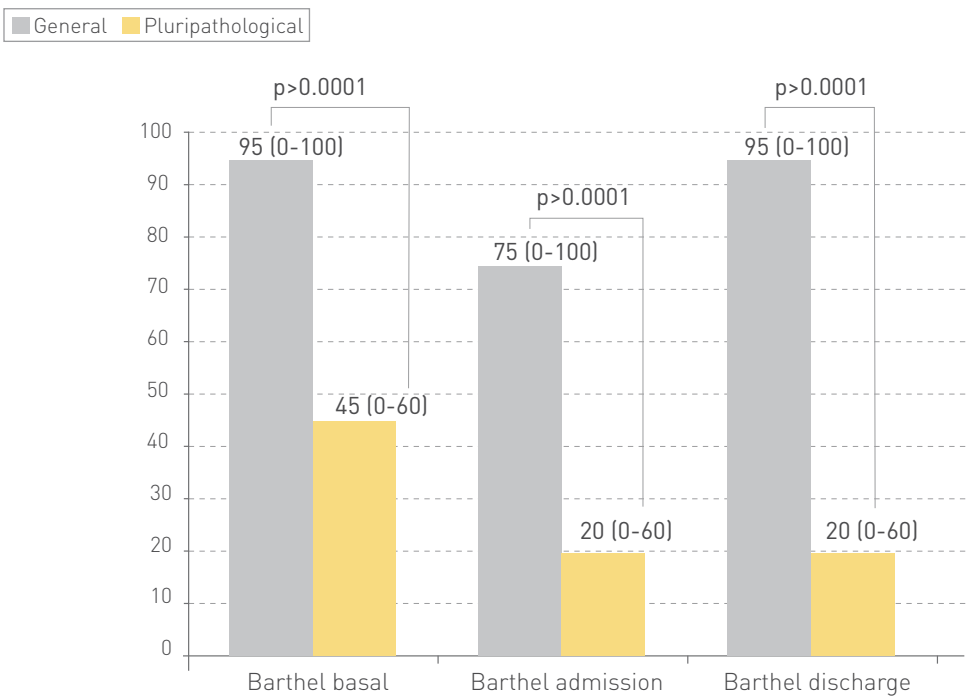
Recently it has been demonstrated that mortality rates amongst hospitalized polypathological patients are significantly higher during hospitalization than in patients who are not hospitalized, irrespective of the cause of hospitalization. The factors

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/]. 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 a 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

PATHOLOGY	SCORE
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 metastasic 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 comorbidites. 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.

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.

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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

Figures and Tables

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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]

-Contents-

When people live with multiple chronic diseases:

a collaborative approach to an emerging global challenge

This book is continuously evolving at www.opimec.org

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