Jan De Maeseneer

FAMILY MEDICINE AND PRIMARY CARE

At the Crossroads of Societal Change



For Anita

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Content

Foreword	7
Introduction	II
Chapter 1 : A Personal View on the History of Family Medicine and Primary Care <i>Jan De Maeseneer</i>	13
Chapter 2 : Dealing with Social Determinants and Diversity Jan De Maeseneer, Sara Willems, Veerle Vyncke, Stéphanie De Maesschalck	39
Chapter 3 : Goal-Oriented Care: a Paradigm Shift for Multi-morbidity? Jan De Maeseneer, Pauline Boeckxstaens	55
Chapter 4 : Decision-Making in Care and Prevention: a Complex Task Jan De Maeseneer, Veerle Piessens, Stefan Heytens	69
Chapter 5 : Towards a Socially Accountable Pharmaceutical Industry? Jan De Maeseneer, Thierry Christiaens	83
Chapter 6 : The Quality of Care and the Care for Quality Jan De Maeseneer, An De Sutter	103
Chapter 7 : Training (Family) Physicians and Health Care Professionals for the 21 st Century <i>Jan De Maeseneer, Peter Pype, Myriam Deveugele</i>	121
Chapter 8 : Policy Change: from Care for Individuals and Families towards Accountability for a Population <i>Jan De Maeseneer</i>	145
Chapter 9 : How to Pay Family Medicine and Primary Care? Jan De Maeseneer	163

Chapter 10 : Family Medicine and Primary Care in an International Context	
Jan De Maeseneer, Peter Decat, Anselme Derese	185
Family Medicine and Primary Health Care at the Crossroads of	
Societal Change Jan De Maeseneer	201
Epilogue Jan-Jakob Delanoye	215
Curriculum Vitae: Professor Jan De Maeseneer An De Sutter	221
Thanks	225
List of Acronyms	227
Endnotes	229

Foreword

Family medicine and primary health care made major advances since the Alma-Ata Declaration of the World Health Organisation (WHO) in 1978.¹ What was initially seen as a sound principle – to structure health care from the community level in response to the needs of individuals and populations – turned out to be a determining factor of effective, efficient, safe and timely health care.² With WHO's reconfirmation of primary health care as the core component of health systems in the World Health Report of 2008,³ the international development of primary health care with a central role for Family Medicine within it truly got under way. This book reviews and critically appraises these developments.

The 40 years since 'Alma-Ata' largely overlap with the history of the World Organisation of Family Doctors (WONCA), which was founded in 1972. Over time, a strong alliance has grown between WHO and WONCA to support the restructuring of health systems from hospital-centric to community-based.⁴ This is still very much a work in progress, with few formal evaluations to date. This book, based on the author's impressive international track record, comes at an important time, as reflective personal experiences and observations are very valuable contributions. The excitement of international primary health care development is in applying the general principles of caring for all individuals for all health problems at all life stages, while integrating prevention, promotion of health, care and support in a person- and population-centred approach over time and in a way that adapts to the local context. The local community is a core determinant of the final outcome of this process of change. In its ten chapters this book covers the various aspects of primary health care development - from regulating the health system to the teaching and education of (future) primary health care professionals.

The importance of this book should be seen in the light of two fundamental lessons that have been learned from international primary health care development. First, the process of changing from hospital- to community-based health systems is challenging and requires coherent policies. It has to address regulatory issues such as how to ensure access to health care and the affordability of health care. It also involves defining indicators that allow measurement of the process of system change over time. This process of change requires

close collaboration with community leaders, academics, health funders, health professionals and other stakeholders. Consistent policy is required, in which all the various aspects are addressed as interrelated components. Changing the health structure without training adequate numbers of health professionals with the skills and competencies to practice in the primary health care setting, or providing specialty training without a regulated role for family physicians in the health system, will substantially hamper the performance and ongoing development of the health system, and the capacity to provide universal health coverage.

Secondly, primary care and family medicine are highly complex fields. The successful development and implementation of policy require that this complexity is understood and respected. The impact of primary care and family medicine is not just in the process of health care, but in the outcome through improvements in the health status of individuals and communities, their functioning, and autonomy. What people can do themselves should not be taken over by professionals. Interventions should not be provided just because of their availability, but only when they contribute to people's health status. When the provision of disease-specific interventions is replaced by responsiveness to individual and community needs, the orientation of care can be directed at and evaluated in terms of individually specified goals.

The essence of the professionalism and effectiveness of family medicine is in understanding individuals and communities and sustaining trusted relationships with these constituencies. Professional concepts go well beyond the traditional medical reference of diseases and interventions, as is true for the markers of quality primary health care. In the end it is always back to the basics: the person, family, and local community. Social conditions are the main determinants of health and disease, and even within close geographic proximity, communities may substantially differ in their social conditions.⁵ A major contribution of primary care to population health and well-being is in including this awareness in the health care provided to individuals.

The 40 years since Alma-Ata, and the organisational life history of WONCA, span also the professional and academic career of the distinguished author of this book, Professor Jan De Maeseneer, our colleague and friend. Jan not only lived through this period, but has been a creative maestro orchestrating the development of primary care and family medicine as a global movement.⁶ The

ten chapters of this book represent the various domains where Jan has made his academic mark. This book testifies to his leadership. At the same time it is a monument to his many magnificent contributions. There is no better way for the international community of primary health care to commemorate his farewell from the Chair of Family Medicine and Primary Health Care at Ghent University.

Professor Amanda Howe, President of WONCA 2016-2018 Professor Michael Kidd, President of WONCA 2013-2016 Professor Rich Roberts, President of WONCA 2010-2013 Professor Chris van Weel, President of WONCA 2007-2010

Introduction

This book tells the story of family medicine and primary care, as I have experienced it, explored it, learned it, practised it, taught it, changed it and – to some extent – also lived it. The first chapter describes the journey of the 65 years behind us. In the following chapters topics as varied as social determinants of health, Goal-Oriented Care, making a diagnosis, the social accountability of pharmaceutical industry, the care for quality, the organisation of primary care, physician payment systems and global primary care are discussed. Each chapter starts with a "(patient-)story" and ends with a reflection from an expert in the field. The chapters are co-authored by (former) staff members of the Department of Family Medicine and Primary Health Care at Ghent University. However, I take full responsibility for the content of this book.

The chapters are built on a mix of scientific facts and subjective perceptions of someone who was actively involved and tried to make change happen.

Although in some continents there are important differences between general practitioners (meaning someone with only basic undergraduate medical training in most African countries), in this book we use "family physicians" and "general practitioners" interchangeably, both indicating a professional specifically trained to fulfil a comprehensive medical function in primary care.

The final chapter looks at the way forward, exploring why nowadays, more than ever, the world needs strong primary care.

This book wants to contribute to the reflection on how to create societies based on social cohesion, focusing on what really matters: peace, connectedness, compassion, solidarity, social justice, truth and hope for a sustainable future for all.

Jan De Maeseneer

Chapter 1: A Personal View on the History of Family Medicine and Primary Care

I knew Ann-Mary for many years in the practice. She visited regularly for neck pain, sometimes she had worries about the two children growing up, she worked in a bank, played tennis, and was what one could call "an exemplary patient". On a Monday morning in March 2000, she visited me with a story of increasing pain situated somewhere around the stomach, but radiating to the back. Her anxiety and the information that "this was a different type of pain than what she was used to", alerted me, and I referred her for immediate medical imaging. Two hours later, she came back, and the diagnosis was clear but at the same time devastating: "Stomach cancer, already involving the liver and the diaphragm". The following eight months were filled with hope and despair, but most of all were marked by her courage. The oncologist, the resident, the nurse, we all participated in her journey, from surgery over chemotherapy, and finally the decision to go for a palliative approach. The interaction with her husband and children, looking at the past, dealing with the present and already preparing for the future, made us the privileged partners in what human beings are able to cope with, to share, to fear and to celebrate.

Ann-Mary took the lead and organised the care. She had the courage to testify in front of the students what this disease meant to her and her family, creating one of those moments that shapes the students' future profile as physicians.

And then she decided to stop therapy, because it did not help, and to choose "quality of life". Ann-Mary appreciated everything that made her life comfortable and was grateful for the days she could enjoy with her family. Between Christmas and New Year, she died peacefully at home in the arms of her husband and children.

Her husband recently reminded me of this painful episode: "We still miss Ann-Mary so much!"

I Was Born on 30 June 1952

I was born on 30 June 1952 in a local hospital in the city of Ghent in Belgium, the second child in a family that later had 6 children, and contributed consistently to the "baby boom" of the fifties. The study career of my parents ended at the age of 14-16 years, as the Second World War started. They married after the war. My father had a job at a newspaper, where he gradually became the deputy general director, and my mother stayed at home, to take care of the children. Our parents gave us the opportunities they did not receive themselves and enabled us to go to secondary school and to university. We all graduated at Ghent University.

It is noteworthy that in 1952 the delivery was performed by the family physician and a midwife, illustrating the comprehensiveness of the discipline of family medicine in those days. Family doctors were male and took care of the individuals and families they all knew very well "from the cradle to the grave". They mainly provided reactive care, responding to the dominant disease pattern: acute (infectious) conditions like influenza, pneumonia, sinusitis,... Family physicians had an in-depth knowledge of families and were consulted for a lot more than "biomedical diseases". Doctors had to advice on what school the children had to go to, on whether it was a good idea to move to another building, they were asked for advice in case of job loss,... Counselling about "family planning" was another in those days new task, but not an easy enterprise, as a family physician reported; "Oh yes! There was the contraceptive pill. But we, doctors, were very conservative and in the beginning we thought the contraceptive pill is unnatural. When I graduated in 1960, our professor of gynaecology told us that there was a medication to regulate irregular menstruation and 'maybe you could prescribe that in exceptional cases, when it is really indicated to use this for some sort of family planning⁷'. The first patient who asked for the contraceptive pill I refused the prescription, but finally, we had to accept it". Family physicians acted at "the crossroads of societal change" during that period, probably one of the most important changes in the twentieth century!

At the Same Time in the United Kingdom: Development of General Practice (GP)

In the United Kingdom (England) Collings described the development of general practice in the fifties.8 He started his article as follows: "General medical practice is a unique social phenomenon. The general practitioner enjoys more prestige and wields more power than any other citizen, unless it be the judge on his bench. In a world of ever-increasing management, the powers of even the senior manager are petty compared with the powers of the doctor to influence the physical, psychological and economic destiny of other people... General practice is unique in other ways also. For example, it is accepted as being something specific, without anyone knowing what it really is. There are no real standards for general practice. What a doctor does, and how he does it, depends almost wholly on his own consigns". And then follows a "grim analysis of present position and future prospects". But the recommendations are positive: "First, an attempt should be made to define the future province and function of general practice within the framework of the National Health Service. Secondly, basic group-practice units should be formed as soon as possible. There is real urgency about launching this experimental work; for relatively soon the new patterns of hospital and specialist care will be firmly established, and everything will be fitted into them. If that happens it will then be virtually impossible to do very much about general practice".

The concept of "primary care" also originated from the United Kingdom. Already in 1920 Lord Bertrand Dawson proposed three hierarchical levels of "care location" (primary, secondary, tertiary). He first identified "primary care as the most basic level of a structured health system, concerned with caring for common problems in outpatient settings".⁹

In the Netherlands the fifties saw a strong development of general practice/ family medicine. At the start in October 1956, the Dutch College of Family Medicine decided to organise the famous Woudschoten-Conference, that finally led to the definition of the function of the family physician: "To accept the responsibility for a continuous, integrated and personal care for the health of individuals and families, which they are accountable for. This care focuses on the prevention when possible and a cure of disturbances in the health status of the individual and the family (a threefold task: to cure, to rehabilitate and to prevent)".¹⁰ It is amazing to see how "modern" the vision of some of the participants at that conference was. So was the vision of Buma, who described an "anthropological diagnosis": the description of somatic issues, an analysis of the psycho-functional situation, and an "ecological description". Querido¹¹ sees the patient as a person integrating the somatic, the social and the psychological field. Comprehensive care does not mean that the physician should address everything on his own, but that he should deliver care in co-operation with social workers, psychiatrists and mental health professionals. Finally, the Woudschoten-Conference defined 12 tasks for the family doctor (see box 1).

Box I. Tasks of the family doctor, according to the Woudschoten-Conference

- 1. Primary care in the broader sense, including addressing psychological traumata.
- 2. Somatic examination.
- 3. Psychological and ecological examination that requires appropriate skills in communication and history taking.
- 4. Registration and management of all medical data.
- 5. Differentiation in 2 approaches: one group that can be approached according to daily routine, and a group that requires specific approaches because of the complexity of the problems.
- 6. Treating what the family physician is able to address.
- 7. Task delegation to medical and other providers, but with maintenance of the co-responsibility.
- 8. Making a plan for follow-up in concordance with the medical specialists involved and taking care of its execution.
- 9. Integration and co-ordination of the care for the patient, for the disabled by appropriate co-operation with other providers.
- 10. Contributing to prevention.
- 11. Contributing to health promotion and education.
- 12. Continuous professional development recognising the possibilities and limitations.

Countries like the United Kingdom, Denmark and the Netherlands took two measures that helped the discipline of family medicine to develop: the organisation of care based on a "patient list system" and a "gatekeeping" mechanism, meaning that patients could not access a specialist doctor without a referral letter by the family physician. In Belgium and France these conditions were not fulfilled, which led in the 1960's to a progressive "erosion" of the discipline of family medicine, because the developing technology and the possibilities for interventions in hospitals confirmed Collings' warnings.

In absence of a sound scientific underpinning family physicians worked "experience driven", exploiting the opportunities of the strong personal relationship with individuals and families which provided them with a lot of "contextual evidence". Increasingly, family physicians addressed psycho-social problems, inspired by new developments like the "antipsychiatry"-movement and the ideas of Thomas Szasz, as developed in the *Myth of Mental Illness* (1960) and *The Manufacturer of Madness: a Comparative Study of Inquisition and the Mental Health Movement* (1970), emphasising the right to self-determination and questioning the medical metaphors that label behavioural disturbances as "diseases".

May '68... and Dreaming about a Community Health Centre

I was studying at the secondary school when May 1968 marked the student movement in Berkeley, Paris,... Books like Herbert Marcuse's *One-Dimensional Man: Studies in the Ideology of Advanced Industrial Society* (1964) criticised consumerism, arguing that it is a form of social control and that the system we live in may claim to be democratic, but is actually authoritarian in that view that individuals dictate our perceptions of freedom by only allowing us choices to buy for happiness. This results in a "one-dimensional" universe of thought and behaviour in which aptitude and ability for critical and oppositional behaviour wither away. One of the ideas formulated in this book was "The Great Refusal", when Marcuse makes clear that individuals must develop a new radical subjectivity, so as to create the conditions for social transformation: The Great Refusal is fundamentally political, a refusal of repression and injustice, a saying no, a noncompliance with the rules of a rigid game, a form of radical resistance and struggle.

The ideas of the "tiers-mondistes" like Frantz Fanon and Helder Camara brought the global perspective to students' actions. Most inspiring were teachers in the secondary school who started innovative ways of teaching: small group work, using what happens in society as the starting point of an educational reflective process,... Student participation in secondary school was one of the landmarks in the movement towards "democratisation" of the school and I became the president of the "Students' Council" at our school. The role models by teachers, as well as the "student movement" bringing all secondary schools in the city of Ghent together, in order to change content of curricula and make it more relevant to understand the societal challenges, was very inspiring. Paul Heirwegh, our Latin teacher, stimulated me to explore in my final "maturity exam" historical evolutions in an essay comparing "imperialism" in the Roman Empire as described in "Ab Urbe Condita" by Titus Livius (Ist Century BC) with the work of Helder Camara, an advocate of liberation theology, fighting for the poor and for Human Rights and democracy during the military regime (Brazil – 20th Century). Theoretical concepts were put into practice through fund-raising for the support of liberation movements in developing countries, like Frelimo in Mozambique, SWAPO in Namibia, MPLA in Angola and ANC in South-Africa. All these experiences shaped my world view in those days.

When I started to study civil engineering in 1970, it soon became clear that this could not be my future. I tried to share issues on social justice, human rights with fellow engineer students, but they were not interested. The "hidden curriculum" did not stimulate critical thinking and the study load was huge.

Contacts with students who were active in the follow-up of the May 68-movement in the Faculty of Medicine and who looked for innovation and change in health care delivery, inspired my choice to shift to the studies in medicine. To be honest, I started to study medicine with the aim to change the health care system. But during medical training I discovered that I loved to take care of patients and to address health problems.

From the first medical year onwards we organised a "Social Working Party", looking at social determinants of health and how it affects the health of migrants, prisoners, unemployed people,... Later on, we started the "MORDICUS-student working party", looking at how we could change the curriculum (organising "alternative lectures" debating the need for a new professionalism and more "social justice" in health), but also engaging in reflection on a new perspective for the profession of medicine.

In the framework of a project of educational innovation in the undergraduate programme at Ghent University, under the leadership of Professor Karel Vuylsteek (Social Medicine), groups of students had to analyse a relevant problem that could make a difference in health and society. Our group was working on the topic of "Community Health Centres" and published a report in 1974 where we proposed that "A community health centre is a co-operation of different health care providers (nurses, family physicians, social workers, physiotherapists,...) working together on an equitable basis as far as function, impact on policy and financial reward is concerned. The aim is to realise a comprehensive (psycho-socio-somatic) care of people living in a neighbourhood focusing on health literacy and empowerment, in order to contribute to a health care system, involving the population of the neighbourhood in the governance. We defined a neighbourhood as a group of people with similar interests and needs living in the same geographical area". This concept of Community Health Centres was inspired by experiments such as the "Local Centre for Community Health: Pointe-Saint-Charles" in Montreal (Canada), by primary health care centres in the United Kingdom and in the Netherlands. In follow-up of this document, interprofessional working parties started to reflect with students in nursing, medicine, physiotherapy and social work on how a Community Health Centre could offer an innovative perspective for professionals in health care.

Friday 24 September 1976: medical students occupy Ministry of Health

In the seventies, there was no formal training for family medicine in Belgium. In 1975, the conservative medical trade unions, under the leadership of Dr A. Wynen (in those days president of the World Medical Association), proposed a "revalorisation of family physicians", through an increase with 20% of the feefor-service tariffs for family doctors who had followed one hundred hours of "additional education". The regulation stipulated that the family doctors only had to follow these one hundred hours once, and then they would be allowed to increase their tariffs for the rest of their career. For the organisation of Dr Wynen, this was a strategy to enlarge his organisation, that mainly consisted of specialist doctors, with family physicians. But that was not the end of the story: he also developed the idea of a post-graduate training for "specialist-family physicians" that would become the 26^{th} "speciality" in medicine in Belgium. By doing so, the "family physicians" would become one of the specialties and the ongoing debate about a gatekeeping role for the family doctor could be stopped. The idea was that the trade unions of doctors would organise the post-graduate training for family doctors themselves, consolidating their influence on the training of specialist doctors with a new track for family physicians. The Minister of Health decided to put the debate on the agenda of the High Council for Specialist-Doctors, where the position of the organisation of Dr Wynen was dominant.

The students did not agree at all with this development. Already in March 1976, there was a manifestation by medical students in Brussels, where they asked for an improvement of the 7 years undergraduate training, before a debate about post-graduate training could be considered. Moreover, the plans for the post-graduate training were that 50% of the training would take place in hospitals, that were in need of "cheap labour". The students opposed to the idea that there would be 2 types of family physicians: one with low-tariffs (without any additional training) and one with "higher tariffs".

In September 1976, a document on "Specific criteria for the training and recognition of family physicians who want a special qualification in the framework of the National Institute for Health and Disability Insurance: NIHDI" (meaning: the right to access higher tariffs), was published.

The students could not agree with the document, especially because there was only 6 months training in family medicine labelled as: "The trainee will help a preceptor in family medicine during 6 months".

In order to stop the process, the students of all the medical faculties in Belgium decided to occupy the meeting room of the High Council of Specialists that would debate the proposal on the 24th of September 1976.

At 6 p.m., the 50 delegates of the High Council of Specialists that were supposed to meet were sitting in the meeting room in the centre of Brussels,