

Health Systems & Care for Chronic Diseases

Report of a workshop, 27-30 November 2009, Antwerp

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Introduction

Chronic Diseases (CD) are increasingly being recognised as a neglected global health issue and a particular concern for low and middle income countries (LMICs) (Banatvala and Donaldson 2007; Daar et al. 2007; Quam et al. 2006; World Health Organisation 2005). The emergence of chronic conditions has serious implications on health systems (HS) in those countries. Four out of five CD-related deaths occur in LMIC. People in these countries tend to develop diseases at younger ages, suffer longer – often with preventable complications – and die sooner than those in high income countries (World Health Organisation 2005). The principle response was initially focused on population-wide prevention and promotion, as the most cost-effective strategies (Beaglehole et al. 2007; World Health Organisation 2009). Only very recently, the question of how to address the care needs of people with chronic diseases in LMIC has been receiving increasing attention (World Health Organisation 2005). The organisation of care for these conditions is a growing concern for providers, managers and policy makers in health systems in those countries.

We observe the search for responses to these challenges, in the form of research proposals, training courses and requests for assistance in the organisation of care for chronic diseases at operational level. Some people have been working for several years on specific aspects of chronic care delivery, others have just started. Yet, the body of knowledge and evidence on this theme is piecemeal and fragmented. For that reason, a 2 days' workshop was organized by the Institute of Tropical Medicine and 18 partner organizations from North Africa (Morocco), Sub-Saharan Africa (Uganda, Congo, Ethiopia), Asia (India, Cambodia, Philippines), Latin America (Ecuador, Cuba, Venezuela) and Europe (Belgium, Switzerland). The main objectives of this workshop were to share experiences from different contexts for an initial situation analysis, to explore frameworks & methodology and to define an action agenda. The discussion and the report are structured around four themes: conceptualization, organisation of care, role of community and factors beyond the health care system.

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1. What are chronic diseases and their challenges to health systems

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What are chronic diseases?

Although the need for action and pragmatism is prevailing among many of us, it is useful to be explicit on what the issue at stake is. There are many different (complementary) perspectives possible on what is a Chronic Disease (CD). Striving for one common definition is neither feasible nor useful, but clarification about the specificities of and the variety among CDs is helpful for the orientation of action. One premise mentioned is that the conceptualisation and classification of CDs should respond to the local context and needs of actors in the HS.

'Disease' - biomedical, psychosocial, individual and collective dimensions

Who defines what a 'disease' is? Patients, communities, professionals, researchers and politicians have different methods of doing so. The word 'disease' does not cover the perception of the patients, as does the word 'illness'. Both definitions limit the problems to an individual bio- psychological scope, but leave out some important collective and social problems affecting life and wellbeing of communities, like poverty or violence. But how far do we go in our labelling a phenomenon as a CD/problem? Do we view disabled or aged persons as 'sick' or is it part of the normal variability among mankind? What about 'unproductive adults' or 'socially non- adapted individuals'? A reflection on what is 'normality' leads to the statement that wellness and disease are part of a continuum. Definitions of 'normality' are strongly determined by the social and cultural context. From a pragmatic point of view, 'abnormality' is defined as a deviation from an (objectively determined) value and the (subjective) experience of patients is another, not less important, matter. However, the epidemiological definitions of 'normality' are also subject to debate. In addition, the perception of the patient might determine his search for health services, as is illustrated by the observation that a malnourished child is rarely a reason to visit a health centre in many African settings.

Scientific developments also influence the definitions. The availability of new pharmaceuticals to influence biomedical risk factors in an early stage, the increasing expertise to identify risk genes and the increased knowledge about social determinants of health influence the perception of (the acceptability of a certain state as) 'normal' or

not. Boundaries between risk factors (e.g. impaired glucose tolerance) and diseases (e.g. diabetes) become diffuse.

Alternative criteria could be the need for long term support or the presence of suffering. Along these criteria, Alzheimer's disease might and Down's syndrome might not be a CD. In many European countries, the frail elderly are an increasing group of people needing care. If we return to the collective dimension, can we call a society that constantly exposes its members to toxic environments a chronically ill society?

'Chronic' – what does it mean?

'Chronic' relates to the time-span of disease development /presence, but where and how are the boundaries defined? Acute and chronic diseases are ends of a continuous spectrum. Many CDs have a slow, insidious onset. When do CDs like drug dependence or obesity begin? Are asymptomatic periods, e.g. in autoimmune diseases, part of a CD? Does 'chronic' mean life-long? If so, then the only CDs are those without a cure. Scientific developments change the chronicity of diseases. On the other hand, CDs also have acute episodes. We need a continuum of interventions for a continuum of deterioration. We could use the term 'chronicity and continuity of care', in contrast to 'episodic illness and care'. The differences in kind of care needed are both quantitative (longer time-span, more resources needed) and qualitative (a more important role for the patient, a combination of biomedical with other factors). The metaphor of two cars going on a long journey might be useful: a brand new four wheel drive (a healthy person) and an old pick-up (a person with a CD) aim for the same destination. The journey towards this destination will be very different for each car. Along the road, drivers can make use of technical resources (health services) for maintenance and for repair, but in the greater part of their journey they will be on their own.

Classification

The conceptualisation of CDs influences their classification. The dominant biomedical paradigm considers diseases as caused by *external* factors, based on the knowledge about infectious diseases, and sees the human body as a collective of various organs that can be affected by (multiple) specific diseases. Etiologic and epidemiological classifications follow this line. An alternative paradigm, the systemic and holistic one, looks at patients as persons with their particular history and their belonging to a specific social group and culture. Disease is seen as the failure of *internal* balance or adjustment to context conditions. In the holistic paradigm, people don't fight diseases, but manage them, thus changing the roles of health professionals and patients. This paradigm focuses on processes (including personal/social history) and on the person, more than on the disease. It is less concerned with a particular disease and its distinguishing features, but looks for patterns in the variety of diseases and classifications according to

more comprehensive, systemic or syndromic groups, recognizing their multi-causality (e.g. food related chronic diseases). It also means that interventions include medical treatment, behavioural actions, inter-sectoral actions and political action to address social determinants. For the organisation of prevention, it might be useful to distinguish diseases in the way they progress, e.g. the occurrence of different stages, danger of acute deterioration, etc. There are still other classifications, based on other criteria, such as the burden of disease (usually expressed in QALYs or DALYS) or their economic or social impact (stigma). Underneath the criteria of classification systems are different political views on the approach to disease and the response of the health system.

The role of a health system in relation to CD

Reflecting about the role of HSs implies thinking about the relationship between people and the HS and the role of participation. Different paradigms include the classical schisms between the 'right and / or duty' of people to participate. Who should be helping whom and who is a resource to whom? In pluriform HSs, the answer is mixed, depending on the situation and the actors. Organisation of quality care for CD is an opportunity to assess and reshape the functions of a health (care) system and the division of tasks between levels of care. This can only be useful, if based on good analysis of context and if structures are created with accountability vis-à-vis the population and communities.

Although views about the role of the HS in relation to CD might be very holistic, the focus of the workshop is on *care* for chronic diseases. Care for CDs probably holds somewhere between cure, preventing deterioration and support of impaired or weakened functions, focusing on the functional outcome and capacities of people. It can be argued that Chronic Disease Care (CDC) has characteristics different from episodic care. These relate to specificities of the diseases (CDs often have an uncertain prognosis, and feature exacerbations and asymptomatic periods), to the patient (who has an important influence on course of disease) and to the aims of care (management of disease instead of cure, balance of disease management with other life activities). The recognition of these specificities has consequences for the organisation of care. Important aspects are the involvement of patients in their own care, the coordination and organisation of care and the involvement of other actors and disciplines. Since these aspects are generic to many CDs, the differentiation between different CDs is less relevant for the organisation of CDC. Especially in settings where resources are scarce, a core question is how to organise CDC in a feasible and sustainable way.

Other functions of the health care system were mentioned: to detect people with a CD; to prevent and manage the progress of CD (important in relation to cost-rationing) and being responsive to the needs of people. In the care relationship between care provider (health services as a whole or the individual health provider) and the other party (the community or the individual patient), we should address the power balance between the two (van Olmen et al. 2010).

Key messages & Research issues

Clarification about the specificities of and the variety among CDs is helpful for the orientation of action. Specificities relate to the diseases, to the patient and to the aims of care.

Use the term 'chronicity and continuity of care', in contrast to 'episodic illness and care'. The differences in kinds of care are both quantitative and qualitative.

Organisation of quality care for CD is an opportunity to assess and reshape the functions of a health (care) system and the division of tasks between levels of care and to rethink the concepts of primary health care, participation and empowerment.

2. Organisation of Health (Care) Systems for CD

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The present response of HSs in LMIC to CDs

At present, there is a big knowledge gap about how HSs deal with CDs. But situation analysis from different contexts highlight a number of common problems. The burden of CD is high especially in urban areas and also among the poor. But the lack of adequate and reliable data hinders a more precise overview of the extent and distribution of CDs in the population. In many LIC, there is little awareness in the community about the existence of CDs, risk factors and prognosis, symptoms and possibilities for management. This contributes to the late presentation of patients.

The response of HSs comprises mainly the development of national programmes to manage categories of CDs. Realisation of those programmes is difficult due to lack of budget, lack of integration etc. The routine practice is that chronic care in the public sector is mostly provided at secondary level, based on a medical model with very little time, place and personnel for communication. There are limited referral options from the first to second line, because of geographical spread, vertical programmes and fragmented structures. The gap in public provision at the first line is filled by private providers of all kind. Their care, especially of informal providers and drug-sellers, is usually restricted to the provision of symptomatic medicine for a short term, leading to large out of pocket expenses for patients on a regular basis. Fragmentation and segmentation are a consequence of inadequate public funding and a lack of regulation or coordination, both at the policy and operational level.

Besides the inadequate number and their incomplete knowledge and resources, the attitude of many health workers is an obstacle to better quality CDC. While private for profit providers have mixed motives in the offer of CDC they give, some public health workers tend to adopt a fatalistic attitude towards patients. HSs are traditionally centered around physicians, with a minimum involvement of other actors. In the prevailing medical and bureaucratic culture of these HS, the potential of people themselves to be involved in their own care and of other community organisations is under-utilised. The anticipated interaction between doctors and the population in the designated participation structures does not materialise.

(Re)organisation of HSs for a more adequate response

CDC – the existing models and their usefulness for real HS

A basic premise in CDC is that the patient plays an important role in his own illness management. The most widely used models for the organisation of care for CDs are based on the Chronic Care Model (CCM) of Wagner (Wagner 1998). The CCM is useful to look at the level of a health care organisation. It describes how to organize health care at this level, recognizing the organisation as part of the community, and pointing at six main tasks: self-management support, delivery system design, decision support, clinical information systems, health service reorganization, policies and resources). This (re-)organisation should aim at productive interactions between an informed activated patient and a prepared, proactive practice team. The WHO has made an adapted and enlarged version of the CCM for low income countries (Innovative Care for Chronic Conditions (ICCC)) (World Health Organisation 2007). Their aim is to make it relevant and acceptable for LIC, to be useful in different contexts, for many different CDs. Identifying actions for actors at different levels in the HS, it is especially useful for planners.

The documentation about implementation of these models in practice of CD care is limited to high income countries (HIC). This evidence shows that application of (parts) of the CCM leads to better quality of care, but it is difficult to disentangle the effects of the different components of the intervention. The number of elements implemented and the extent of implementation of these elements vary, depending on many contextual and organisational factors. Several other pilot experiences in low and middle income countries (LMIC) are described in the literature, which usually follow a biomedical approach and are health-service based. These pilots do contain certain elements of the CCM approach, such as training and guideline development, task delegation and decentralization, the development of patient registers, adherence support and self-management.

The models are neither complete nor a prescription on how to organize care. Later authors observed that the models lack, for instance, attention for community based primary prevention, provision of long-term care, and suggestions on how to deal with the progressive aspect of CD. To become useful, the models need to be adapted to a real HS. The confrontation of the model with reality calls for knowledge of the context elements, of the strengths and weaknesses of the implementing organization and of the available mechanisms to implement change. The first step is to map and evaluate ongoing practices through the glasses of the models, after which one could see how the model can be applied. High quality CDC in limited resource settings needs to be a balance between a standardized and a customised / contextualized approach.

Differentiate functions of care

Since CDC is very broad, it is useful to differentiate functions of care, in order to get a good overview of the different aspects of care which are needed. The following functions are part of CDC:

- timely diagnosis: use of (community) screening and other methods;
- clinical / medical management, including pharmaceutical and supportive diagnostic services and including palliative care;
- prevention of progression in the individual patient: in our vision, all functions between primary prevention and rehabilitation are part of a continuum, along the progress of the disease;
- treatment support: including retention in care, self-management and peer support
- psychosocial support, including the embedding in the local/cultural/religious context
- dialogue between health services, patients and community, at different levels and about different aspects;
- disease-specific functions (eg dietician).

Identify actors in care

The different functions of CDC can impossibly be fulfilled by a solo operating health provider and will be the result of efforts of different persons, professionals and lay people. Ideally, these people work as a team or have at least regular contact. A wide variety of persons can be involved, such as case managers, clinical staff, staff of other medical services such as the laboratory or pharmacy, adherence counselors, social workers, psychologists, patient organisations, expert patients, peer-educators, family members, community groups, etc. It is good to map actors which are present in the local context who are or who could be involved in the organisation of care. The composition,

initiation and coordination of a care team depend on the type of CD and on the local available resources and context.

Since many functions of CDC are generic, there is generally no need for separate teams for specific CDs at the first line. In specific contexts, it might be feasible and desirable to establish separate clinics / teams for groups of CDs with common determinants, probably at the second line. The delineation of functions at different levels in the HS is important. Task-shifting has proven feasible for HIV AIDS, for diabetes and for some psychiatric disorders. Conditions for successful task-sharing are a clear definition of which tasks can be performed at which level and to provide training, guidelines and supervision. In order to have actors function together successfully, it is necessary to improve the capacity especially of the non-medical actors and to sensitize all staff, especially the medical actors, to function in a team. It is also useful to realise the limitations of what can be expected from actors. Medically trained doctors might not be prepared, even after further training and sensitisation, to carry out prevention tasks. Also at horizontal level, there is need for coordination, especially between the public and private sector. Professional associations (if present) might play a role in motivating private practitioners to collaborate with the public sector.

Be realistic

It is easy to be swept away by dreams about the ideal form of care, without taking into account the limited resources in the settings of LMIC and human behaviour resistant to change. Recommendations and interventions need to be relevant, realistic, feasible and sustainable in the context of LMIC. Which strategies to use is very context dependent. For example, while 'universal evidence' might say that community screening for early detection of most CDs is not cost-effective, this might be very different in settings with high prevalence. Besides that, community screening can also have additional aims, such as creating contact moments with the community to create a dialogue and awareness. Without losing the clinician's view of being responsive to individual patient's demands, we should have a public health perspective, aiming for the biggest gains for the whole population, taking equity considerations into account. Two important issues from that perspective are: how do we ensure universal access to CDC (coverage of health services, timely diagnosis, etc) and how do we ensure continuity of care?

Key messages & Research issues

The burden of CD in LMIC is high, but the lack of adequate and reliable data hinders a more precise overview of the extent and distribution of the problem.

The present HS response for CDs in many LMIC is characterized by: a public response focused on prevention programmes; little consideration for the organisation, coordination

and regulation of health care services; routine medical practice without attention, the opportunity and resources for the specific aspects of chronic care; and large out of pocket expenses for patients.

Useful models for chronic care exist, but they need to be adapted to the context of real HS in LMICs. Differentiate functions of care and identify actors in care at different levels and between actors at the same level in the HS.

Search for the right balance between standardized and customized approaches to care for chronic patients. Combine the clinical and public health perspective in realistic answers to the challenge of ensuring universal access to continuous CDC.

3. Role of the community

Contributions by Jean Macq, Maurits van Pelt, Pedro Villasana, An Piessens, Adolfo Alvarez Pérez, Everd Maniple, Josefien van Olmen, Bart Criel, Guy Kegels

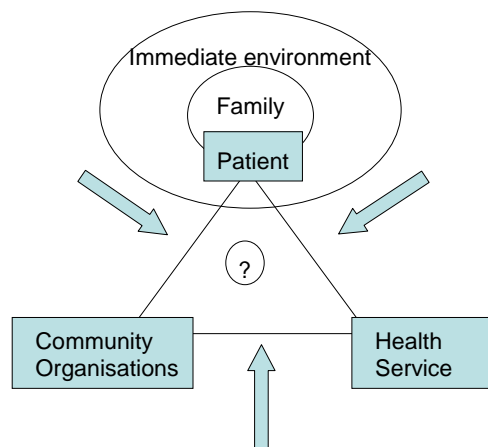
The concepts ‘community’ and ‘participation’

The notion of ‘community’ is very shaky and diverse. It often refers to ‘people living together in one place’, but ‘communities’ are flexible constructs and people can belong to different communities at the same time. How do people relate to these communities? There are different conceptual views on participation. Is it a right or a duty? This relates to how one looks at the relation between state and community, which is ideally one of citizenship, in which people have rights and responsibilities. In many settings, strategies for community participation in the health sector have limited success. People show opposition to participate actively, continuously and intensely in plans or programmes designed by government or NGOs and sometimes even withdraw and return the given responsibility. A possible reason is that communities lack the feeling of having control, ownership and decision-making power. The relationship between the organizing party and the population often remains one of dependency, instead of autonomy.

If participation is considered as a right, including political empowerment, then HS should try to support people who are already trying to do something. They should support the emergence of things happening in the community. This also recognizes the fact that people face other problems and priorities than health alone. Emergence puts the focus on planning as a process, and not so much on (predicted) outcomes. It seems to be difficult for public health workers to ‘let things emerge’, instead of planning and organisation of things for a (predicted) future. The community is often regarded as a ‘target’, for example for health promotion or screening, or as a target for resources to be mobilized. In reality, there is continuous exchange between community and the HS and is it not useful to make a rigid separation. Who needs who and who finds resources where, who is responsive to whom and who supports whom?

The challenge is to find the balance in the process of participation between instrumentalist and empowerment / 'right to health perspectives' and between a top-down and bottom-up approach: HS trying to tap resources in the community and communities claiming resources from HS. These issues are not unique for CDC, but the aforementioned characteristics of CD make participation not only more necessary but also more possible. Patients have different perceptions and expertise about their condition, their needs and how to deal with this condition than professionals who deliver health and other kind of care to them. A person living with a CD gathers expertise in how to deal with his condition in daily life: he becomes an 'experience expert'. His expertise is qualitatively different and complementary to that of the professional. The engagement of patients while recognizing and using this complementary knowledge has an added value compared to most task-shifting approaches, in which activities identified and selected by technical people, are delegated to non-professional people.

Actors and functions



In an attempt to structure our discussion about the community, we propose a scheme to classify groups of actors and their relations. These groups each have their own role and can perform functions of CDC in accordance with this role, in which reciprocity is an important issue. Palliative care, psychological support and practical advice are naturally taken up by patients and their families in many communities. Diagnosis and clinical management are tasks of health services. Community organisations could play an important role in primary prevention and guiding people in the appropriate utilization of health services. Actors in the immediate environment can be employers, colleagues. Other community actors are (in)formal leaders and local authorities. The realisation of functions is determined by the local context conditions. For instance, adherence to HIV AIDS care is often organised by health services, but in some villages in Mozambique

local patient groups carry out this function. If HS are short of resources, they can create alliances with community groups. As said above, the delineation between the different angles is fluid. Some individuals can take multiple roles, being for instance patient and carer. Patients who organise themselves in groups for peer support and other functions become community organisations. The model visualizes the importance of a balanced development of and interaction between all three vertices of the triangle.

How to make it work?

The central challenge in participation is to create conditions for people to optimise the social capital that is hidden in the community. Who is to stimulate and facilitate the interaction between the actors (brokerage role) and how to reduce the (perceived) capture of processes by interest groups? Fruitful and sustainable interactions are built on trust. The balance between actors will depend on the functions of care focused on and on the context. If there is a strong local health system with a coordinating public health officer, he is probably the initiator. In the Cambodian example, it is a community organisation. Other initiatives in which interactions between different actors is crucial, such as mutualities, often have an external party involved. This actor might, apart from bringing additional resources and new ideas, be perceived as neutral and thus acceptable for other actors.

The experiences in many contexts with community health workers make us doubt the effectiveness of voluntary participation, without any benefit in return. How to organize sustainable involvement of people from the community (patients or general) in the organisation of care? Making them part of a local structure might lead to some kind of institutionalization and durability, but it might also weaken the voluntary and non-professional character which is the strength of many initiatives. Sustainable participation means not only sharing roles but also responsibilities. Research questions are: what are suitable incentives to maintain commitment, how long do 'volunteers' last in their role, what is the best profile of 'volunteers', what is the effect of making networks between volunteers?

In the last decade, patients themselves have become a resource of volunteers and have been given names of 'expert patient', 'peer educator' etc. Intuitively, the concept of involving patients in care seems very promising, for several reasons. Patients might have a direct benefit and stronger incentives in becoming a volunteer for their own situation. The success of MoPoTsyo (see below) shows that people feel in charge of the problems and the programme. In addition, people with CD have different perceptions and expertise about their condition, their needs and how to deal with this condition than the professionals and this complementary expertise can be very helpful for other patients. In certain contexts, patients could also be more credible and trusted by the local community than health providers. If patients become care givers, they take up an additional role next to being a patient. The notion of power and agency relating to these

combinations and shifting of roles has to be investigated. These hypotheses need to be tested in different contexts. In the Cambodian context, the fact that PEs themselves experienced a state of health similar to the patients they talk to and that they managed to arrive at a better level of functioning is a source of inspiration and credibility, for themselves and for other patients.

Experiences from different contexts

Peer Educator Networks in Cambodia

Cambodia is a Low Income Country (LIC) with a high burden of diabetes and high blood pressure, of which many people (70%) are unaware. The HS is pluriform, but very patchy. Public and private for profit (PFP) health services offer care for acute incidents. There are a small number of private non-for-profit health services and a few, often not well trained, private providers who offer care for CDs. The coverage of CDC is estimated to be maximum 10%. The challenges of CD for the Cambodian HS are to increase access to CDC and to improve the quality of the presently provided CDC. Any strategy developed should take into account the affordability for patients (3-5 USD / month) and the feasibility for the HS, in terms of demands on professional work force capacity. In this context a local NGO, MoPoTsyo, was established to tackle these challenges.

MoPoTsyo has developed community-based interventions which are linked to accredited health providers, by using the human potential in the society. Diabetes patients are trained to become Peer Educators (PE) in their own community. They go into their community, to find and assess new patients (with basic screening methods) and to transfer knowledge and skills in coping with diabetes and high blood pressure, and they facilitate weekly group sessions where old and new patients meet. The screening is an occasion to start a dialogue with the community. The PE and the new patient meet regularly in the first period, to see how the patient can manage his blood glucose levels with lifestyle changes and to arrange an appointment with a trustworthy health provider, if necessary. Patients can receive medication from a revolving drug fund against affordable prices. The PEs form networks among themselves and they are supported by a programme manager. There is a medical doctor attached to the organisation, who trains the PEs and is available for consultation. PE receive a reimbursement of their cost and a modest financial incentive.

The organisation started in an urban area but has expanded to rural area since mid 2007. At end of 2009, it had covered a district area with 133,000 inhabitants. There is one PE in every health centre, covering more than 550 people with diabetes. The PEs had screened 98% of the district population and the results in terms of physical parameters (HbA1c) and coping skills (knowledge and lifestyle changes) are positive. Monthly health expenditure of the people went down and people were satisfied with the programme. On average, a registered patient consults the professional health services

2.3 times per year. The PEs provide most of the services and function as a gate-keeper. In general, one can say that the project works and that it does not increase the burden for the HS. It has not only led to early diagnosis and care for people with diabetes, but also to empowerment of PEs (and patients) with regard to their own disease. Main weaknesses of the programme are the narrow view of health problems; the limited training and subsequent risks or errors by PE which are easily multiplied in the network and the weak coordination with the primary care level. Despite these, it would be interesting to explore if this experience could be extended to other contexts and to other CDs.

Community involvement in health promotion in Venezuela

An experiment is discussed in which community participation for health is tried out at a radio station, also to see whether and how this experiment could be used in future health policy. Observations were made about the process and practices developed and about the actors and their perceptions. More than a thousand reporters contributed to the development of a seatbelt campaign. Having developed it themselves, people report a strong feeling of autonomy in decision-making and ownership, illustrated by sayings like "This radio is ours, it is (owned by) everybody (who) need it" and "We make this radio". There seems to be a strong group feeling and pride among the reporters, possibly rooted in the values guiding the whole communication process. The relationship between the people participating in the radio experiment and the involved institutions seems to be based on respect.

The media have developed an important role in the Venezuelan political and social context, but they have lost a lot of credibility among people in recent years. Lessons from the radio experiment for other health programs, policies, and strategies, also for CD, are that the institutions need to be creative in looking for new ways to relate with communities and people, with respect for people's own knowledge and their autonomy.

The burden on informal care-givers

With the increasing burden of CDs and the present (inappropriate) organisation of many HS, community involvement and particularly family caregivers are the primary source of especially chronic (long-term) care and, in some settings, have even been seen as a solution for the shortages of resources in the HS. However, the increasing burden of CDs and societal transitions such as the participation of women in labour out of home and urbanisation results in a change in balance between the caregivers and people needing care. As a consequence, the pressure on caregivers is increasing.

Informal caregivers are an important resource for the HS and we should be aware of the potential burden that is placed on them, physically, mentally, socially and financially. Caregivers are subjected to stress, less wellbeing and physical health, relationship and

personal strain and depressive symptoms. They are sometimes called hidden patients, because they rarely seek professional help. Based on Yates (1999), Ribesse et al (article in progress) developed a framework for interventions both for CD patients and their informal caregivers at macro-level (raise awareness, advice regarding existing government schemes and epidemiological research), meso-level (training, networks of families for mutual support, respite care) and micro-level (support, education and advice). Despite this, there are probably limits to what we can ask from informal carers and we should be careful not to overburden them. This is probably not a luxury limited to HIC, but may be needed in many contexts in LMIC as well.

Key messages & Research issues

Stimulating participation is also supporting the spontaneous emergence of evolutions in the community. CDs are an opportunity for participation of patients themselves, because of their direct benefit, their complementary expertise and their credibility. There are limits to what we can ask from voluntary actors, especially from informal carers.

HSs, patients and the community are not separate, but linked entities, which can tap resources from each other and in which there is a certain degree of reciprocity. People can take up different roles at the same time, which influences agency and power balances of actors.

How to create conditions for people to optimise the 'social capital' hidden in the community, for the benefit of people? Who is to stimulate and facilitate interaction between different actors in care? How to sustain the involvement of 'volunteer' actors?

What is the effect of patients also taking up care-giving roles to other patients, on themselves, on other patients and on the patient – provider relationships? How does it influence the effectiveness of care models?

4. Beyond the Health Care System

Contributions by Mariano Bonet, Carl Lachat, Pol De Vos, Karen Pesse, Josefien van Olmen, Guy Kegels

Determinants of CDs

The generally slow progression and long duration of CDs provides many opportunities for interaction to prevent a deterioration of condition. From that perspective, a distinction between health promotion, primary prevention, treatment and rehabilitation is less relevant; they are part of a continuum of management of health conditions.

The development of CDs is influenced by determinants at different levels: by the general socio-economic, cultural and environment context (eg globalization, urbanization, ageing); by common modifiable risk factors (unhealthy diet, physical inactivity and tobacco use); by unmodifiable risk factors (age, heredity) and by intermediate risk factors (eg raised blood pressure, raised blood glucose, abnormal blood lipids, obesity) (World Health Organisation 2005). This classification suggests spheres of influence related to the individual and his direct environment, to social and community networks and to the policy level. Inequities play a major role, but the differentials between and within countries are poorly understood.

Human behaviour is central in the increased incidence in many CDs, in particular those that are diet related. Recently it was again shown that one third to half of the diabetic cases could be reversed or prevented with increased physical activity and a healthier diet (Knowler et al. 2009; Misra 2009). Health providers and promoters often focus on the individual as the primary cause of an unhealthy diet or a sedentary life style. However, evidence from intervention studies underlines the limited effect of interventions targeting the individual. Increasingly, the living environment is being accepted as the major determinant adversely affecting diet and lifestyle. Very often, the options for an optimal lifestyle are simply not available. Limited access to healthy foods (be it physical or economic), safety and cultural issues hampering physical activity, poor city planning are just a few examples.

Lessons from experiences in different contexts

Research, national action and political commitment in Cuba

In Cuba, the political commitment for better health is high, at national and local political levels. The government puts considerable resources into the national health system of public providers. CDs have been recognized as a problem since the eighties and regular nationwide surveys to the common risk factors have been performed. There is an intersectoral research programme and a national health program for the management of risk factors and the health determinants up to 2015. It promotes an integrated approach, focusing on health services reorganization to include promotion and prevention (strengthening the role of family doctor and first line health services, a modified function of the policlinics) and on inter-sectoral action and social participation, managed by the government. In terms of care, non-communicable disease management takes place at all levels of health services. The major antihypertensiva and streptokinase are produced locally, and acute care is present in most municipalities. One concrete outcome is a continuous downward trend in coronary heart disease since 1982.

National nutrition policies – Europe, USA and elsewhere

A well-documented example of the influence of an adequate policy response is the Karelia project in Finland, where the curve of mortality rates of coronary heart disease showed a markedly increased decline from the introduction of a focused health policy (Puska 2002).

A global analysis of existing nutrition policies highlights the disparity in action plans and in particular the absence of strategies on chronic diet related diseases at the national policy level. Some countries in Europe have an exemplary comprehensive policy plan involving all sectors and developed in a very participatory way. Examples of good components of a nutrition policy are the systematic follow-up of certain indicators among target groups in specific environments (Danish indicator program for nutrition surveillance), a program against obesity, in family/community, in schools, in business/ in the health system (Spain), actions to improve availability and access to health food in neighborhoods and schools (USA) and an integrated food/nutrition policy for health and environment: healthy and sustainable (Sweden) (Lachat et al. 2005). These initiatives share a well developed multidisciplinary approach and environmental focus. Among LMIC, there are consistent policy documents in Niger, Swaziland, Mongolia, Cabo Verde, Congo.

How to optimise the environment?

This needs first of all recognition of the fact that the environment is important in shaping the behavior of individuals. Next, there is need for joint action, policy making and regulation. The WHO database of national policy documents on nutrition may provide guidance for LMIC, especially for the process how to develop a national response. The consultation phase is very important, which can be organized in different ways, according to the institutional settings and levels of decentralization. Denmark, UK and France have an extensive English version of their policy, available online. Regulation is necessary with regard to advertising, the media and the food industry, in the present context of globalization and interdependence also at international level. Health professionals, especially those working in public health, could cross these bridges, by providing evidence; by creating awareness about the interrelation of problems and the responsibilities and potential roles that actors have, by advising in policy-making and, finally, by not to forget the individual patients. The relationship between risk factors, the development of CD and health outcomes is complex. The patient himself has a big influence in the course of many CD. This makes it difficult to determine the expected results of disease management. It will be a balance between autonomy, life expectancy, quality of life, in which the opinions of health professionals, the patient / his family and of health planners might differ.

Inter-sectoral approach

Ideally, health is mainstreamed in other policies, meaning that other sectors take into account the effects on health in their activities, for instance city-planning or school-programmes. This can be done in different ways, to different extents, from 'health informed policies' to systematic health impact assessments. In Cuba, health is a quality indicator in the development of all policies. On the other side, other sectors and actors should be involved in the development of health programmes. Examples are the involvement of parents, teachers and the children in the development of a program for obesity in children.

There are barriers at both sides in this dialogue. Professionals from other sectors might not feel competent to deal with health-related issues. Health professionals from their side are generally not well equipped to promote the inter-sectoral approach, don't consider the wider implications of their health-related advice and are not inclined to take into account other views or shared decision-making. The advice to 'eat fish twice a week' is not coherent with sustainable fishery, for instance. A good example is making explicit the link between sustainability and health (Wilkinson et al. 2009). Other possibilities to stimulate a fruitful dialogue between health-related and other professionals are to involve actors, who might 'break the ice' and widen the scope of view. This means also to include subgroups in the population, traditional health providers, social networks, etc. Patients themselves can play an effective role in primary prevention of CD through increased awareness. This is being done in Cambodia by diabetic school teachers, who have been trained as peer educators and who in turn promote healthy lifestyle among school teachers, in order to improve the health communication with the school children.

To involve different community actors in a common dialogue is well suited for determinants that can be easily discussed in the public sphere, but more difficult to do with chronic social health-related problems which carry a taboo, like alcoholism, domestic violence, etc. Although media attention to critical incidents contribute to raising these issues on the agenda, it is very difficult to achieve community action. There can be even a tension between a high profile public debate and a practical approach to solve concrete problems, which often benefit more from a certain degree of discreteness.

Dialogue between research and policy

It is a challenge to have scientifically sound and complete evidence prevailing over commercial lobbying and selective scientific evidence, identified as a 'toxic combination of policies, programs and politics' (World Health Organisation 2008). Scientific institutions need to be able to function independently from the political power structures, yet at the same time be able to interact with them.

Besides direct interaction with decision makers, there are other ways to influence policy making. An example is the use of media, especially internet. The wide reach makes this

a very powerful medium to influence opinions and behaviour of people and actions of organisations, such as private companies. Blacklists and greenlists, for example for the food industry, are both useful, enabling the public to make healthy choices.

Key messages & Research issues

CDs provide many opportunities for interaction to prevent deterioration: health promotion, primary prevention, treatment and rehabilitation are part of a continuum of management of a health condition.

Determinants of CDs and opportunities to influence those relate to the level of individuals and their direct environment, to social and community networks and to policy levels. Inequities play a major role, but the differentials are poorly understood. There is a big global disparity in action plans and strategies to address the determinants of CD.

How to mainstream health in other policies? How to ensure interact with decision makers at different levels and with the general public, so that sound policies are made and followed by action?

Conclusion

The increase in CDs is to a large extent the result of development and successful health action in the past. The set of CDs is so large and diverse that 'net positive result' is not so easy to conceive of. Getting older does not automatically mean living longer and better lives. However, we can help people a lot in improving the lives they live and preventing untoward developments. We can learn from strengths and successes but also from mistakes and weaknesses. We can also learn to take different perspectives (learning from diversity) and in this way have a fresh look at our own system. Areas for research include: understanding the genesis of many instances of chronicity (not just statistical correlations); describing differentiated reality; understanding differentials; introducing 'net positive effect' changes (which ones and how?) and how to evaluate them.

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