
**CHRONIC DISEASE – ASPECTS AFFECTING THE ORGANIZATION OF
MEDICAL CARE**

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Abstract: Background: The Chronic Care Model (CCM) is widely accepted as the universal operational framework for health systems to address the increasing chronic disease burden. According CCM chronic diseases are defined very broadly to include any conditions that request ongoing activities and response from patient, personal caregivers, as well as response from medical care system. Starting point of chronic disease management in our country is an Order of Ministry of Health with a list of diseases according International Classification of Diseases, revision X (ICDX) and patients with any of these diseases should be under dispensation. This article discusses which aspects of chronic diseases, affecting the organization of medical care, are not taken into consideration in the current rules for chronically ill patients. **Method:** A qualitative approach was taken using focus groups as the data collection method. **Results:** The participants identified the need to be considered more clear, extended and comprehensive criteria to include chronic conditions for dispensation. These criteria should be flexible, and take into account the unpredictability of the course of the disease and its individual severity, patient's social situation, multimorbidity, goals of therapeutic approaches, including health promotion.

Conclusion: The results present current situation and add new ideas how different aspects of chronic disease affect the organization of medical care. They should be evaluated as a sensitive indicator of the need to reconsider the whole process of inclusion and care for patients with chronic conditions.

Keywords: chronic disease, long-term care, public health, focus group

INTRODUCTION

Global and national health bodies are developing standards, norms and guidebooks to introduce programs to meet the challenges faced by health systems in providing efficient services to patients with long-term conditions. The Chronic Care Model (CCM) is widely accepted as the universal operational framework for health systems to address the increasing chronic disease burden.

Bulgarian health care system has undergone a significant reorganization in the last few decades, with changes in the structure and financing, but still kept some approach from the past like dispensary treatment or dispensation. The definition is given in the Law on Health and it states: "Dispensary treatment is a method for active investigation, diagnostics, treatment and periodic monitoring of patients with certain diseases". The ongoing supervision of chronically ill people - dispensation, with rules described in regulations issued by the Minister of Health and in the National Framework Contract where is provided information about all mandatory actions within each calendar year [1,2].

According CCM chronic diseases are defined very broadly to include any conditions that request ongoing activities and response from patient, personal caregivers, as well as response from medical care system, more traditional physical disease – diabetes mellitus, or mental disorders, some include addictions or unhealthy habits; the CCM presents approach across diseases, based on common features [3].

Starting point of chronic disease management in our country is an Order of Ministry of Health with a list of diseases according International Classification of Diseases, revision X (ICDX) and patients with any of these diseases should be under dispensation[4].

This article discusses which aspects of chronic diseases, affecting the organization of medical care, are not taken into consideration in the current rules for care chronically ill patients.

MATERIAL AND METHODS

A qualitative approach was taken using focus groups as the data collection method. We planned on conducting focus groups until data saturation.

The selection of participants was made with the idea of a heterogeneous and informal group. The following categories of participants were invited in writing – general practitioners, specialists from different fields, working in either hospitals or ambulatory care settings, health managers, health economists and patients. A form was provided with information on the process for the focus groups, including written informed consent.

Preparation, including a literature review, enabled development of key questions on the care and treatment of chronic diseases.

Five focus groups ($n_1=11$, $n_2=11$, $n_3=10$, $n_4=13$, $n_5=15$) were conducted in January-June 2013 and lasted average 74 min. Three moderators, working in pairs, with familiarity in group dynamic and discussed topics, facilitated sessions. Audiotaping was performed.

For descriptive purposes, all participants were asked to complete a pre-session list to gather the following information presented in (Table 1)

Table 1. Distribution of the participants

No. of group	N of participants	Gender		GPs	Specialists	Patients	Institutions			Health managers
		M	F				RHI	BMA	RHIF	
1	11	4	7	9		1	1			
2	11	3	8	7					2	2
3	10	3	7	1	4	2				3
4	13	4	9	1	4		1	2		5
5	15	3	12	3	2	1	1		1	7
TOTAL	60	17	43	21	10	4	8			17

RHI - Regional Health Inspection

BMA - Bulgarian Medical Association

RHIF – Regional Health Insurance Fund

The coding of the performance of the five groups was conducted in three steps, using thematic analysis. In the first stage each moderator separately encoded certain phrases from the statements of the participants. The goal was to formulate a set of topics that were considered as key issues for discussion. The second stage was to sort and summarize the topics into categories. There was an optimal saturation of the concepts in the formation of the categories. In the last stage were synthesized themes, a result from the joint work of the researchers, which were discussed and finalized as a result of the discussions in the focus groups.

RESULTS

One advantage of the quality research is the opportunity to uncover unexpected themes.

The first aspect that has been raised in the discussion was “the duration”. One of the questions was how long the condition had to be present before the patient could be involved in the chronic care program. The second dimension of “the duration”, related to the distinction between a chronic disease which lasted for a period of time, and one that was life-long – whether both should be under dispensation. The other side of “the duration” was how diseases shorten the life expectancy of the patient. All groups discussed the issue of lack of cure or incurability. The participants described this as “for life”. This means that the patient must live constantly with the condition. And the participants shared the opinion that it is for this type of chronic diseases has to be specific programs.

The other aspect with chronic disease was identified as the boundary between the individual and the “social dimensions”. The groups focused in particular on the difficulties created for the families of patients, and felt that family members should also be included in the process of providing care for the chronic patient.

Aspect, agreed to be important for organizing medical care for chronic diseases, was ‘the degree of severity’. This was directly related to forecasting and the establishment of forecasting models and it is one of the aspects that allow personalization in the management of the chronically ill patient.

The group did not fail to discuss the aspect “multimorbidity”, which is often present in patients with chronic diseases and requires a specific approach during medical care.

There was a noticeable trend in the work of the focus groups to seek aspects of chronic disease through medical care. An interesting line of discussion was the inclusion of “the goal of medical care” as an aspect. The focus groups suggested goals such as slowing the progress of the condition, reducing suffering and extending the life

of the patient. The social adaptation of individual patients, who having a chronic disease, was suggested by some of the participants as the ultimate goal of medical care programs.

“Health promotion and general preventive activities”, relating to chronic disease must also be included as an aspect in the programs to manage chronically ill patients.

DISCUSSION

Focus groups were chosen due to their ability to elicit unique perspectives on the study subject, originating from interactions between participants.

The participants connected chronic disease with multiple aspects, expanding the definition, far beyond the disease codes of the ICD. This suggests that establishing a proper long-term care system requires a large-scale approach towards chronic disease.

Most definitions of chronic disease are complex - at least 3 months of illness or slowly and constantly developing over a long period of time, but also - its course is unpredictable, and unlike acute diseases, it cannot be cured completely [5]; slow development, lack of complete cure and dissemination [6]; irreversible presence, either accumulation or long-term latency of medical conditions or disabilities, which in view of the supporting therapy, requires the whole environment of the patient to encourage development of his personal skills, maintain functional abilities and prevent further damage [7]; last more than 3 months, typically show, incurability, cause difficulties in everyday life, dependency and expenses [8,9].

In the current list of diseases which could be under dispensarization are included more than a hundred ICD codes, separated for children and adults, part of them chronic for a period of time or hereditary. Discussed in the focus groups aspect “duration”, described as “for life” point out that, no matter which term will be used, imposed in our country - dispensary or management of chronic disease, it should be referred to chronic disease that is implicitly connected with a permanent need for medical care, medications, and psychosocial therapies, provided by a multidisciplinary team. Every patient with such chronic illness manifests the disease slightly differently, and uses medical services at the different levels of the health system, whether primary, secondary, inpatient or palliative care.

The significance of the problem is determined not only by “the duration”, but even more so by the effect of the disease on the daily life of patients. The social aspect was widely discussed by the groups. In the literature, these two aspects are often combined, to give definitions such as: “the disease is chronic when the condition impairs the everyday life of the patient in physical, psychological and social aspect for a period longer than six months” [10].

Chronic diseases are generally associated with serious restrictions in daily activities, particularly in the ability to work. In classifying the disease, it is important to note the way in which it is viewed by the individual concerned, and its effect on their ability to work, as well as subjective assessments of health [11]. The responsibility and self-control of the patient are crucial in determining the degree of dependency [12].

The patient’s family members are often care providers, but even when they are not, the emotional impact on them is still significant; as they are often also overwhelmed by a sense of hopelessness and loss of control [13]. It is likely that the effect on family members is negative, but in some families, it seems to strengthen the relationships. In general, the impact of chronic disease is either not identified or underestimated by medical experts. The focus groups paid particular attention to this aspect, and social adaptation was discussed as a potential goal of medical care, given the need to adjust all aspects of everyday life to physical suffering, functional insufficiency, the feeling of loss, worries, and sadness of both patients and their families. Another important issue is the financial one, including funds needed for transport, therapy, adaptation at home, and possible hiring of help [14].

Although the groups felt that the individual severity of the illness should be considered in redefining chronic illness for chronic care programs, the psychological aspects of chronic disease were not discussed. Studies of adaptation to chronic disease show that there is often significant difference between the level of dysfunction of the disease reported by the patient and the established pathological deviations. The level of the physical, mental and social problems of patients with chronic diseases vary significantly from one patient to another, even when patients have the same clinical condition with the same severity. The weak connection between biomedical parameters and physical, psychological and social well-being suggests a hypothesis about the importance of psychological factors in the health of patients with chronic diseases [11]. Another question, which was not widely discussed in the focus groups, but has significance for the individualization of care and is often discussed in the literature, is the ability to cope with chronic disease, particularly how the patient sees him- or herself in the new situation. The impact on the family and their need for support are always associated with chronic disease. This aspect needs to be evaluated alongside the individual management and the personal responsibility of the patient [14]. Studies show that it is more important how the individuals react to the situation than the exact nature of the chronic illness [6].

Multimorbidity is a problem directly related to the providing of care for chronic diseases. In most of the available programs for managing chronic disease, this problem is not taken into account and recommendations on care are focused on a specific condition. The health consequences of multimorbidity are not well studied. For example, few studies have considered the way in which diseases can potentiate others, so that the degree of disability becomes more complex and often more severe [15]. Special attention was paid to the interrelation between chronic disease, expensive treatments and the consumption of health services more generally.

The complexity of the chronic illness is determined to a great extent by the impact on the life of the individual and of the community, and especially the level of incapacitation. This often focuses on chronic disease as a long-term health problem, with slow progress, which can be controlled, but not cured. Healthcare provides the means by which functional status is improved, symptoms are minimized and aggravation is reduced. Discussion in the focus groups suggests that the extension of the aspects to include goals like these might improve the motivation of health providers to care for the increasing number of patients with chronic diseases. Various goals have also been identified in the literature, including reducing the risk factors, optimizing the quality of life of the patient and preventing complications and co-morbidity¹⁰ or secondary prevention of complications, and improving functional capacity¹⁴.

Another aspect which also should be taken into consideration, and which was common to both the focus groups and the literature, is that there should be a discussion of health promotion and changes in the patient's lifestyle, for which medical practitioners must be specially trained. Healthy lifestyle behaviors among patients with chronic conditions can improve patient outcomes, lead to clinically meaningful results, and reduce costs and burden on the healthcare system [16,17].

CONCLUSIONS

The CCM can be applied to a variety of chronic diseases, identifying the essential elements of a health care system that encourages high quality chronic disease care - the community, the health system, self-management support, delivery system design, decision support and clinical information systems. These six elements are both complex and inter-dependent, acting on both medical specialists and patients.

Bulgarian model of chronic disease management, dispanserization, is based on list of disease and the participants in focus groups identified the need to be considered more clear, extended and comprehensive aspects like criteria for inclusion of chronic conditions into it. These criteria should be flexible, and take into account the unpredictability of the course of the disease and its individual severity, patients' social situation, multimorbidity, goals of therapeutic approaches, including health promotion.

The results obtained in this study through qualitative research via focus groups present data and add new ideas how different aspects of chronic disease affect the organization of medical care. They should be evaluated as a sensitive indicator of the need to reconsider the whole process of inclusion and care for patients with chronic conditions.

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